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AUTHOR Ness, Jean E.
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ABSTRACT

The sixth in a series of federally supported modules for training paraprofessional school personnel who work with students with disabilities, this module presents information on working with individuals who are medically fragile or have physical disabilities. Both a facilitator's edition and a student's edition are provided. Chapter 1 examines the changing roles of education related to students with disabilities. Chapter 2 investigates national demographics related to disabilities. Inclusive language is discussed in Chapter 3. Chapter 4 provides information on disability-related laws and abuse and neglect laws. The role of the school nurse and health paraprofessional are addressed in Chapter 5. Communication strategies and problem-solving techniques are described in Chapter 6. Chapter 7 provides information on teamwork. Chapter 8 discusses caring for individuals with different disabilities. Specific instructions for 10 different health procedures and general instructions for 7 others are provided in Chapters 9 and 10. Chapter 11 presents material on properly administering medication at school. Nineteen appendices provide extensive supplementary material, forms, and articles. The facilitator's edition offers learning activities and information sheets to be used as transparencies. (Contains 46 references.) (CR)

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Module Six

Working with Individuals Who Are Medically Fragile or Have Physical Disabilities

Facilitator's Edition

Prepared by
Community Integration (UAP)

UNIVERSITY OF MINNESOTA

The College of Education
and Human Development

Module Six

**Working with
Individuals Who
Are Medically
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Physical
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Published November, 1995.

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Institute on Community Integration Project Staff

Teri Wallace, Project Director

Richard Weatherman, Project Director

Hutchinson Technical College Project Staff

Carol Adams, Training Specialist

Joyce Evenski, Instructor

Veronica Hansen, Instructor

Susan Rosenzweig, Instructor

Andi Upin, Instructor

Written/compiled by Jean E. Ness.

Edited by Dick Sullivan and Vicki Gaylord.

Publication design by Charles Gibbons.

To request additional copies and alternative formats, please contact:

Publications Office

Institute on Community Integration (UAP)

University of Minnesota

150 Pillsbury Drive SE

Minneapolis, Minnesota 55455

612/624-4512

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Facilitator's Outline

About the Facilitator's Introduction & Outline

This training module contains an outline and a brief introduction to the material designed to assist instructors as they plan and prepare to teach the content of this course. The outline provides overviews of each chapter which include:

- Chapter goals to be accomplished by students.
- Materials necessary to teach each chapter including transparencies, supplemental readings, etc.
- Discussion questions to facilitate class lectures and discussions.
- Topics to be covered in each section.
- Activities to be completed by students both in and out of class.

These items are the same as those appearing in the outside margins of the facilitator's edition of this module. The discussion and activity notes appear in the facilitator's edition only – they do not appear in the students' edition. The text, however, is the same in both. In some cases, the discussions and activities may have been abbreviated in this outline, but provide the same basic information as it appears within the context of the chapter.

This outline can be used when planning lessons. It is a good idea to read through the outline before using it for instruction in order to know what to expect and learn how the material is tied together.

The content of this module is based on a training series piloted in 1993 by Hutchinson Technical College in Hutchinson, Minnesota. Because of this, many references are specific to Minnesota's school and social service systems. We encourage instructors located in other states to replace the Minnesota-specific information with information more relevant to their state.

Section 1

Facilitator's Introduction

In 1975, the Education for All Handicapped Children Act, also known as Public Law 94-142, was passed. It has now been updated and is called IDEA. The law gives all students – regardless of physical or mental disability – the right to a “free and appropriate public education” in the least restrictive environment possible. The passage of PL 94-142 tremendously benefited large numbers of youths with physical or mental disabilities who previously had been under-served or not served at all by the public schools. Recent amendments to the law have expanded the eligible student

population to include preschool students and infants.

People with special health care needs were cared for in hospitals or institutions until the 1980s. These institutions took care of the individual's educational, developmental, and medical needs. Federal, state, and local policies of deinstitutionalization and the movement for health care cost containment have pressured the medical insurance industry to reimburse families for medical expenses incurred when a patient is not hospitalized. Home health care, although costly, is less expensive than hospital care.

Advocates of "normalization" for persons with handicapping conditions feel that, whenever possible, disabled persons should be deinstitutionalized and integrated into mainstream society. For children, this means attending school in the least restrictive environment. Such service settings might include regular classrooms; self-contained special educational classrooms in a regular school; special schools for individuals with mentally or physically disabling conditions; or, when necessary, hospitals or institutions, depending on the level at which the individual with a disability is able to function. PL 94-142 and a various state court decisions now give legal weight to the argument that more individuals with disabilities should be in regular schools. This means that students with severe disabilities are entering public schools in unprecedented numbers. Individuals with disabling conditions and health care needs of varying complexity are being moved from institutions and special education centers and placed in regular schools.

Controversial Issues

As a result of IDEA and a number of court decisions interpreting its intent, many public school systems already provide such non-medical services as toilet training, diapering, assistance with feeding, and training students to perform these basic needs themselves. This is just a beginning: advances in medical technology and procedures have led to higher survival rates for individuals with chronic illnesses and congenital abnormalities, as well as for survivors of trauma. This means that today there are more individuals with long-term health care needs who often require expensive equipment to sustain them.

More and more children with chronic health care needs are entering the public schools as a result of deinstitutionalization, drug and alcohol abuse by pregnant mothers (which causes many babies to be born with anatomical and/or developmental abnormalities), teenage pregnancies (which often give rise to premature or low birthweight babies), and the thousands of children born with AIDS every year. This creates a challenge for those providing services in public schools.

Some of the tasks now required of the public schools must be performed by state-licensed medical personnel. Others require training of non-medical personnel and the use of special equipment. In

some schools, nurses must suction mucous from the airways of individuals who cannot do it themselves. Nurses also must care for individuals who have special breathing apparatus; insert catheters into the bladders of individuals who are unable to urinate; administer insulin or give other injections or medications as required; and insert feeding tubes for liquid nutrition. In some cases, emergency and resuscitative procedures must be established and practiced.

Placement of individuals with medically fragile conditions in the public schools has given rise to several challenges. These include adequate funding, availability of appropriate facilities, new roles and responsibilities for school personnel, lack of appropriate training, as well as legal and liability issues.

These increasing health care demands, coupled with shortages of school nurses, require formal partnerships among all levels of school personnel to provide for the care and well-being of students with medically fragile conditions. The formation of health care teams of primarily non-medical personnel raises additional levels of responsibility for the school nurse. The nurse remains – in all cases – the supervisor in any individual's special health care concern and must always be primarily responsible for the care, training of staff, and distribution of responsibility for the health care needs of the student. The nurse's role in the care of students is to assess the health needs of the child in the school setting and to coordinate with staff, family, physicians, and community agencies to provide a comprehensive school health program that facilitates the maximum educational opportunity for the individual. This responsibility has escalated dramatically over the past sixteen years with the inclusion of more individuals with medically fragile conditions in the school system. The role of the school nurse and the delegation of responsibility is covered in Chapter Five.

Sections adapted with permission from *The Medically Fragile Child in the School Setting: A Resource Guide for the Educational Team*, American Federation of Teachers' Ad Hoc Committee on Health Care Responsibilities in Special Education, 1992.

[Continued]

Section 2

Background Information on Health Impairments in Educational Settings

In recent years, advances in health care technology and procedures have increased survival rates for low birth-weight infants, children with chronic illness, children with congenital anomalies, and survivors of trauma (Gittler & Colton, 1987). Higher survival rates have led to increases in the number of children with temporary or long-term health care needs, including technology assistance (U.S. Congress, Office of Technology Assessment, 1987).

Before the 1980s, children with long-term special health care needs were cared for in hospitals. Federal and state policies of de-institutionalization, cost considerations, and pressure from advocacy groups paved the way for increased use of home health care for children with chronic health problems (Foundation for Hospice and Homecare, 1987). Ireys (1988) has reported that estimates of the number of children with disabilities and chronic illness vary between one and twenty percent of the pediatric population. Specialists in the U.S. Congress' Office of Technology Assessment (1987) estimate that 47,000 or more children require technology assistance each year. Child advocates support normalization of developmental outcomes for children with special health care needs, including school attendance in the least restrictive environment (Halamandaris, 1985). Children with chronic health impairments are entering school systems in unprecedented numbers and have presented unique challenges and opportunities for educational policy makers (Walker & Jacobs, 1985).

Financing represents an ongoing challenge related to pediatric home health care (Cabin, 1985: U.S. Congress, Office of Technology Assessment, 1987). Traditionally, public and private medical insurers covered the cost of hospital care (Munoz, et. al., 1989), while regulatory practices prohibited reimbursement for health care procedures performed at home (Beckett, 1985). Due to pressure from advocacy groups, families, and health care providers who felt that children should be home whenever possible (Shelton, Jeppson & Johnson, 1987), medical insurance practices were revised and reimbursement for home health care costs were allowed. Home health care is less expensive than hospital care, but still costly (Trost, 1988). Costs for health care of children with special health care needs (e.g., children with technology dependence) have been especially high (Trost, 1988). Questions have arisen regarding responsibility for health care costs incurred during school attendance.

Public schools, pressed for funds, may often be reluctant to pay for additional full-time nurses and special transportation vehicles, and to assume legal liability for medical care during school hours. At the same time, private insurers – and Medicaid – will seek to minimize their costs of serving technology-dependent children at home by shifting financial responsibility to the schools. (U.S. Congress, Office of Technology Assessment, 1987)

There have also been challenges related to assignment of roles and responsibilities for carrying out special health care procedures (Committee on School Health, American Academy of Pediatrics, 1987; Johnson, Lubker, & Fowler, 1988; Mulligan-Ault, Guess, Struth, & Thompson, 1988; Palfrey, Singer, Walker, & Butler, 1986). Wood, Walker, and Gardner (1986) conducted a national survey of state health and education agencies to determine the existence of guidelines for select health care procedures in schools: a) catheterization; b) seizure management; c) medication administration; d) respiratory care; e) tube feeding; f) positioning, colostomy/ileostomy care; and h) "others" (including allergy shots). Only six states had written guidelines for all eight procedures, and twenty-six states had either no written guidelines or guidelines for medication administration only.

As the number of children with special health care needs in schools increases, the need for greater clarity regarding role delineation also increases. Educators, health care providers, program administrators, and others have contacted specialists in their respective professional organizations for guidance. In response to this need, representatives from the National Association of School Nurses (NASN), National Education Association Caucus for Educators of Exceptional Children (NEA-CEEC), Council for Exceptional Children (CEC), American Academy of Pediatrics (AAP), and the American Federation of Teachers (AFT) convened a task force in 1988 to examine issues and provide recommendations regarding role delineation for those providing special health care needs. This module represents the recommendations of the task force. It is hoped that administrators, health care providers, and educators will find the information in this training module useful in planning educational programs for children with special health care needs.

Please note that public documents produced by the President's Committee on Employment of People with Disabilities are available in alternative format.

Adapted from "Guidelines for the Delineation of Roles and Responsibilities for the Safe Delivery of Specialized Health Care in the Educational Setting" (1990), in *The Medically Fragile Child in the School Setting: A Resource for the Educational Team*, American Federation of Teachers, 1992.

[Continued]

Section 3

Facilitator's Outline

Chapter 1

Changing Roles of Education

Introduction

Discussion 1

Introduce the unit by discussing the issues and challenges in this introductory session. Many of the students may already be working in situations where they serve individuals with medically fragile conditions. Have them discuss their feelings about and trials and triumphs with these experiences. Ask students what they see as most important to learn from this module.

Section 1: Background Information...

Discussion 1

Students will read this section as supplemental background information on the increased numbers of individuals with disabilities and special health care needs entering schools today. Discuss its contents with the students. Relate these new challenges to their work in schools either as a health paraprofessional or a special education a paraprofessional working one-on-one with an individual who may have special health needs.

Activity 1

Although many of the needs and concerns of individuals with medically fragile conditions are the same as or similar to those of individuals with physical disabilities, special concerns might prevail with an individual with a physical disability. Ask students to discuss key issues and challenges in their work environment (or one in which they hope to work) for individuals with physical disabilities.

Activity 2

After the description of characteristics, emphasize to the students that this is not an all-inclusive list of characteristics. Some individuals with this disability may have some, none, or all of these characteristics.

Activity 3

Ask students to share their experiences in working with individuals who have physical disabilities. Students will use the "Additional Tips" to add the ideas of others in the group.

Activity 4

After the description of characteristics, emphasize to the students that this isn't an all-inclusive list of characteristics. Some individuals with this disability may have some, none, or all of these characteristics.

Activity 5

Ask students to share their experiences in working with individuals who are health impaired. Students will use the "Additional Tips" to add the ideas of others in the group.

Activity 6

Interview a student with a chronic illness and/or his or her family in your community. Formulate a set of questions you would ask to address issues families and individuals face in work and/or school settings. Relate these issues to the paraprofessional's role and ask the individual and/or family members what support they feel paraprofessionals should be to them. Write these responses down and be prepared to share them with the class.

Activity 7

Discuss with the students the importance of understanding where the individual's "coming from" emotionally and physically when they come into the health office for help and support. Explain that this is important for everyone at all ages. Understanding the basics about the disability areas discussed in this module, as well as attaining a level of sensitivity, is essential for best meeting the needs of the individuals. Students will discuss this point and add to the variables listed below during discussion.

Activity 8

Ask students to share experiences about these stages of grieving from work settings or personal settings. Are they similar at all to issues people face in death and dying situations? Brainstorm ways to support individuals through the various stages of grief. Set up role play situations where one student is the individual in one of the above stages and the other student is a health paraprofessional. Have the rest of the class watch and make suggestions about how to handle the individual's needs. Discuss at what point a referral for psychological assistance may be appropriate.

Activity 9

Have each student role play with another student using these

questions. Have the student who is the "interviewer" ask the questions in a kind, concerned manner, trying to get good background information to help the individual in the work/school setting. Remember to tell students that this is a generic form. Students will check to see if their settings have a similar form. You may want to tell students this form would also be useful to fill out or refer to when talking to parents.

Chapter 2

Demographics & Disabilities

Section 1: National Demographics...

Activity 1

Read and discuss with students the facts and attitudes reflected in this national report. Ask students to express their opinions and feelings about individuals with disabilities in the work-force. Explain how special conditions for health issues are dealt with in work environments. Remind students that under federal law, (Section 504 of the Rehabilitation Act and the Americans with Disabilities Act-ADA) individuals with disabilities are entitled to "reasonable accommodations" on the job as well as in schools. For example, it might be an appropriate accommodation for an individual with a medically fragile condition or a physical disability to have an attendant on the job to support him or her.

Chapter 3

Inclusive Language

Section 1: Etiquette and Disabilities

Activity 1

Role play several situations in which the students assist a person who has a physical disability. Have one student play the part of the individual with the disability and one student act out the appropriate procedure to assist. Use different student for each role play situation. Examples of role play scenes might be:
Situation: A person has cerebral palsy and is in a wheelchair. The person is asking for assistance but speaks very unclearly.

The assisting person needs to ask for clarification several times before he or she understands that the individual is asking for help to go to the restroom.

Situation: An individual who is blind is in a demonstration group where everything is typically given visually. The instructor/trainer asks the person with the visual impairment what sort of help he or she will need to follow the demonstration. The individual says he or she needs the trainer to verbally describe all that is being done and he or she can transcribe in on a braille as the demonstration is given. The individual also says he or she will need to be "walked through" the floor plan of the room. The trainer practices doing this with the individual.

Section 2: Inclusive Language

Discussion 1

Discuss how people feel when they hear certain phrases, for example deaf and dumb, or a heart attack victim versus hard of hearing and heart attack survivor. Students will share concerns about use of language to describe. Encourage students to be leaders in setting the trend where they work to use language appropriately. Ask them to "listen" and "read" more carefully in the next few days to see if they notice how language is used to describe persons with disabilities.

Activity 2

Students will read "People First Language" found in Appendix A. Discuss appropriate ways to address individuals with disabilities in writing and speaking. Then Students will read the article "Finding Right Words is Still a Big Struggle for 'Disabled People'" in Appendix B. Discuss the strong feelings those from the disabilities community have about use of appropriate language. Ask students to write a paragraph describing a person with a specific disability using "people first" language.

Chapter 4

Education & Health Laws

Section 1: Disability-Related Laws

Activity 1

Students will read the Fact Sheet on ADA, found in Appendix C, and discuss the main points of the law. Then Students will read Appendix D, "What the ADA Means for People with Develop-

mental Disabilities" and discuss the law's impact on people with all types of disabilities as well as developmental disabilities.

Activity 2

Read and discuss the Section 504 Fact Sheet found in Appendix E and other information with students. Remind students how important it is for the individuals with whom they work to understand their rights under Section 504 and other laws.

Activity 3

Discuss the rights of parents under IDEA. Ask for student input. Relate the knowledge of these laws and their importance to the ability of individuals and their parents to advocate.

Activity 4

Because so many paraprofessionals in schools deal with behavioral challenges, this section should lend itself to discussion. Encourage students to discuss the pros and cons of this ruling and to relate personal experiences. Remind students that the discipline decisions for students they work with should be directed from their supervisor.

Section 2: Laws Relating to Abuse and Neglect

Activity 1

Read and discuss these laws relating to abuse and neglect. Make sure students understand them and their own responsibility for following them.

Chapter 5

Delegation of Responsibilities

Section 1: The Role of the School Nurse

Activity 1

Students will read and discuss this section about the responsibilities of the school health nurse. Make sure the students understand that their duties should be assigned from the nurse and their activities under her or his direction.

Section 2: Planning for Safe Delegation

Activity 1

Read and discuss with students the four ways to delegate. Make sure they understand that the initial delegation comes from the school nurse.

Activity 2

Students will read "Delegation and Nursing Practice" in Appendix F. The delegation of responsibilities for a paraprofessional must come from a licensed school nurse. After students read this description of the school health nurse, read Appendix G where you can refer to the Nurse Practice Act in full and point out key portions of which paraprofessionals should be aware. Explain how this would relate to them in a health paraprofessional position. Discuss the implications for nurses in Minnesota.

Activity 3

Students will complete the following chart by either using their own work experience or setting or by interviewing a school health nurse and health paraprofessional team. Make sure the students have first read the previous sections in this chapter before they do this chart. This is a chart that can be used and kept in the health office for reference or could be kept, in a modified version, as an individual record for specific individuals with disabilities requiring regular medical support.

Section 3: Job Description for the Health Paraprofessional

Activity 1

Discuss the points of this sample job description with the students. Explain the different components. Ask them to add any

other points they feel are important for a professional

Activity 2

Students will read this section and the "Statement on the Nursing Activities of Unlicensed Persons" in Appendix I. Have them relate these rules to the sample job description and discuss it. Then Students will complete the activity "Questions to Ask About a Health Paraprofessional Position" by interviewing a school nurse. After conducting the interview and reading the pages above, Students will create their own job descriptions.

Chapter 6

Communication

Section 1: Basic Strategies...

Discussion 1

Explain to students that a key element to successful working relationships is good communication. Students will read and discuss this section with you and with each other, keeping in mind how important communication is to them on the job. After discussing these basic communication principles, have the students do Activity 1.

Activity 1

Take a clean sheet of paper and draw a line down the middle. Write "my strengths" on the left side and "my weaknesses" on the right. Make a list of your strengths and weaknesses on the job. Include your communication skills as you see them. Share this list with someone on your present job, a family member, or a friend. Be prepared to share this information with the class.

Discussion 2

This material has been added to reinforce the importance of confidentiality, roles, and responsibilities. Remind students of these passages in the training. Encourage discussion on the difficulties that occur when the paraprofessional's put in the middle of situations between setting and home. Brainstorm with students ways to avoid problems. Remind students what is and isn't their responsibility.

Section 2: Problem-Solving Techniques

Activity 1

Students will read "Twelve Barriers to Communication" and discuss these barriers in work, social, and personal settings.

Activity 2

Students will use this situation (or another you make up) to work through the Solution Worksheet on the following pages. After this exercise, ask students to share some reactions to the process of the exercises and some outcomes they had with their partners. Relate these outcomes to actual situations.

Activity 3

The focus of the Breakdown Checklist and the Solution Worksheet is to promote a model for working side-by-side attacking problems rather than people. Students will choose a partner and role play the situation provided (or make up your own situation that better meets the needs of the group). As homework for next session, Students will use another copy of the worksheets and go through this process with the Breakdown Checklist and the Solution Worksheet with their supervisor at work, a co-worker, or a family member if they aren't in an appropriate work setting. Tell students to be prepared to discuss the outcome.

Activity 4

Students will do the activities "One-Way Communication" and "Two-Way Communication". After these exercises discuss what happened. What was the communication like in the first exercise? How did that make the students feel? What was the difference between the feelings students had in the first and second exercises? Ask what they feel caused that difference.

Chapter 7

Teamwork

Section 1: An Example of Teamwork...

Activity 1

Teamwork is as important as communication in determining the success of working relationships. This section will give students some essential ideas about teamwork. Have them read and discuss this section with you.

Section 2: Team Members

Activity 1

Students will look at the sample IHP in Appendix J. Walk through the plan with the students so they are familiar with what an IHP contains.

Activity 2

Refer students to the sample IEP from the Minneapolis public schools/department of special education in Appendix K. Walk through the IEP, explaining how it's filled out and by whom. Depending on the group, you may want to assign roles (parent, paraprofessional, nurse, health paraprofessional, psychologist, student, etc.) and role play the IEP process and fill out the IEP form. Emphasize that the IEP process is an example of team participation. Ask the students what the pitfalls of this team process are and where the health paraprofessional fits into IEP planning. Discuss issues related to paraprofessionals being involved in the meetings. Allow students to air their feelings. Ask for some possible solutions to issues related to involvement in meetings. Relate the team process and the IEP format to the additional individual plans listed.

Activity 3

Discuss each of these points with the group and the importance of each in the role of the paraprofessional in a team work situation. Encourage and allow discussion about these points. There might be a lot of discussion about how the paraprofessional doesn't feel a part of a team and isn't allowed to participate as an active team member. Brainstorm with the group for some positive steps they can take to become a more equal member. Brainstorm for ideas of how a paraprofessional can be a member of a team meeting when the meetings are held at times they cannot attend (i.e., during bus duty, after or before hours). One solution could be for the paraprofessional to develop a written form with his or her supervising nurse to use to relay information about the individual that addresses the paraprofessional's concerns and experiences about the individual.

Section 3: Essential Members of Effective Teams

Activity 1

This section describes who should be on the team – who the members in the teamwork are. Read and discuss each role with the group and ask students if they have other members to add.

Activity 2

Because this is a guideline of roles in a global sense, emphasize that paraprofessional roles will be discussed in more detail later. Also explain that additions to these team members need to be added for a direct care setting. Ask students what other staff members should be added to this team for direct care, or in settings with which they are familiar.

Activity 3

After they have discussed the "Chain of Command" circle chart in Appendix L, ask students to prepare a chart of the team members and their roles on the team in a site familiar to them for the next session.

Section 4: How Teams Really Work

Activity 1

Introduce these elements of effective teams and discuss them with the class. Discuss the difference between independence and interdependence and explain the importance of interdependence in team efforts. Explain how important accountability is on their job. Because they have to be so flexible and respond many supervisors (the nurse, the principal, the classroom teacher, the special education teacher) it is extremely important for them to devise a way to keep track of who said what about whom. Lead a discussion of what methods can be used to keep one's accountability (e.g., a weekly plan with each supervisor to be evaluated at the end of the week, a calendar for the month with assignments, etc.). Encourage students to develop a small team concept whenever possible so the interaction can be more personal. Explain the complex nature of collaboration and how difficult it can be without good communication. Stress the importance of setting up a good communications network with all members of the team and all supervisors. Encourage the students to request time from their supervising nurse to regularly evaluate team efforts.

Section 5: What Paraprofessionals Need to Know...

Activity 1

Discuss each of these task functions. Students will give examples of each. Relate team discussions to both education and health care situations. Make sure students understand these are important functions for team members to recognize regardless of their position on the staff.

Activity 2

Ask for specific examples of these types of positive behaviors paraprofessionals have used in team situations. Tell students that these behaviors are also important when working one-to-one with students or clients. Brainstorm with students about how they can encourage others they work with to use these behaviors more frequently.

Activity 3

Ask students to give reasons they feel team members or co-workers act in the ways described here; ask for examples. Brainstorm for ways to work with people with these types of behaviors. Ask students to relate times they've acted in any of the "anti-group" ways and why.

Chapter 8

Caring for Individuals with Disabilities

Introduction

Discussion 1

This section is set up to provide basic information to the health paraprofessional on a number of diseases/conditions/disorders. Students will read these facts about each and the comments on how this is important to the paraprofessional and then discuss them in class. You could add greatly to this section by inviting individuals with any of these conditions to discuss them, or families who are involved to speak in class.

Chapter 9

Selected Health Procedures: Specific Instructions

Introduction

Activity 1

Discuss these procedures. Ask students for questions and input. Give examples of situations where health paraprofessionals may be asked to perform these procedures.

Section 1: Assisted Eating

Activity 1

Students will read these tips about assisting an individual with eating. Discuss the tips and ask students to draw on their experience for any additional ones that would be helpful.

Section 2: Body Mechanics...

Activity 1

Many of the sections in this chapter deal with individuals with physical disabilities who may require assistance in mobility or in positioning themselves (for activities such as toileting). It's important for students as paraprofessionals to understand not only assistive devices but also proper – and safer – ways of assisting and lifting. Read these sections, and the "Principles of Body Mechanics" and "Ten Commandments of Body Mechanics" found in Appendix M, and discuss them as a group.

Section 3: Bowel Care

Activity 1

Discuss the definition, equipment needed – adding things to the list if necessary – individual considerations and what to ask the individual. Students will add to these sections as appropriate from their experience.

Section 4: Cast Care

Activity 1

Go through each section of cast care with students and ask them to add to the information here based on your discussions.

Section 5: Diapering

Activity 1

It's very important to emphasize these points when training individuals to perform diapering procedures for individuals with disabilities. Go through the following procedures and then discuss them as a group. You may want to demonstrate some of the procedures for clarification. Explain the differences in diapering individuals based on their age or disabling condition. Refer students to the "Diapering Procedures" chart found in Appendix N.

Section 6: Diet Monitoring

Activity 1

Discuss these procedures. Ask students for questions and input. Give examples of situations where health paraprofessionals may be asked to perform these procedures.

Section 7: Glucose Monitoring

Activity 1

Discuss these procedures. Ask students for questions and input. Give examples of situations where health paraprofessionals may be asked to perform these procedures.

Section 8: Hand Washing

Activity 1

These procedures for hand washing are extremely important for all health paraprofessionals to know and understand. Along with this background information, also discuss and refer to the additional information in Appendix O, which contains the flyers "Hand Washing Procedures" and "Hand Washing Steps". These would be useful for class participants to post in their work areas and to share with others.

Section 9: Skin Care

Activity 1

Discuss these procedures. Ask students for questions and input. Give examples of situations where health paraprofessionals may be asked to perform these procedures.

Section 10: Toileting Procedures...

Activity 1

Discuss these procedures. Ask students for questions and input. Give examples of situations where health paraprofessionals may be asked to perform these procedures.

Chapter 10

Selected Health Procedures: General Instructions

Introduction

Discussion 1

Explain to the class that these descriptions are only brief ones because they are procedures that must be taught thoroughly by a nurse and should be performed only under a nurse's supervision. Discuss these procedures and answer any questions.

Chapter 11

Medication Administration

Section 1: Properly Administering Medication...

Discussion

This chapter is very important for students to understand. Be sure to spend time going through all aspects of medication administration to students so they clearly understand what the role of the health paraprofessional should be and what the role of the licensed school nurse should be.

Be sure students understand the preliminaries they must follow before administering medications. Then they should know the procedures to be followed very clearly.

Quiz Unit 1

Multiple Choice: Pick the letter that corresponds with the choice that best completes each statement.

- 1 Public Law 94-142, also known as IDEA, deals with:
 - A All students receiving free and appropriate education in the least restrictive environment.
 - B All students need to be immunized before school entrance.
 - C All students are to be free from abuse and neglect.
 - D All students are screened for vision and hearing.

- 2 There are several general characteristics of physical disabilities. They include:
 - A Poor coordination, below average motor skills.
 - B Poor self-esteem in relation to disability challenges.
 - C Poor relationship skills.
 - D All of the above.

- 3 Susie has a physical disability that requires her to use a wheelchair. To assist Susie, you could:
 - A Encourage a fellow student at lunch to be her partner at lunch to carry her tray.
 - B Expect her to use the washroom in the allotted time as the other students.
 - C Have her sit at the side of the room to give her more space.
 - D Tell students they can push her chair as they want to.

- 4 Bob became blind in one eye as the result of an accident with a BB gun. In the anger stage of grieving, you could expect to see him:
 - A Following all the classroom rules.
 - B Punch out a student on the bus.
 - C Very quiet and withdrawn.
 - D Postponing his medical care.

- 5 Jon has cerebral palsy. It is best to refer to him:
 - A As the "handicapped" student.
 - B As the "CP" kid.
 - C By his name.
 - D As the boy who doesn't talk right.

- 6 A deaf child wants to cross the street. You should:

Unit 1: Answers

1 A	11 F
2 D	12 T
3 A	13 T
4 B	14 F
5 C	15 F
6 D	16 T
7 C	17 T
8 A	18 F
9 D	19 F
10 A	20 T

- A Ignore him.
 - B Sign that he can't go.
 - C Stop the traffic.
 - D Sign him to look both ways and cross the street.
- 7 ADA refers to:
- A Attention Deficit Affiliation.
 - B Annual Disabilities Agenda.
 - C American with Disabilities Act
 - D Americans with Delayed Academics
- 8 Federal Law (IDEA) requires schools to serve children beginning at:
- A Birth
 - B Age 5
 - C Age 3 months
 - D Age 3
- 9 Paraprofessionals are mandated reporters for the Child Abuse Prevention Act. They should remember that:
- A By reporting in good faith they are immune to civil or criminal liability.
 - B As a reporter, their name will be confidential.
 - C They report to their supervisor and social services or the police.
 - D All of the above.
- 10 The Nurse Practice Act states the school health professional receives delegation from the:
- A Licensed school nurse.
 - B Teacher.
 - C Principal.
 - D Special education director.
- True or False:** In the blanks provided, write "T" for a true statement and "F" for a false statement.
- 11 Most adults with a learning disability have a college education.
- 12 The average cost of hiring people with a disability is the same as hiring people without a disability.
- 13 There are more students in school with disabilities now

than there were fifteen years ago.

- 14 People with disabilities have different basic needs than those without.
- 15 The word of choice is *handicapped* vs. *disabled*.
- 16 There is a Minnesota state law that encourages schools to have a behavior intervention plan as part of their IEP.
- 17 School districts of 1,000 or more students are required to have a licensed school nurse.
- 18 When speaking and writing about an individual with a disability, always put the disability first.
- 19 When walking with a person who is blind, hold their arm.
- 20 Offer students an atmosphere of acceptance.

Unit 2: Answers

1 C	11 T
2 A	12 F
3 D	13 T
4 D	14 T
5 B	15 T
6 D	16 F
7 C	17 F
8 A	18 T
9 C	19 T
10 B	20 F

Quiz Unit 2

Multiple Choice: Pick the letter that corresponds with the choice that best completes each statement.

- 1 The state agency that regulates nursing practice is the:
 - A Minnesota Department of Human Services.
 - B Minnesota Department of Administration.
 - C Minnesota Board of Nursing.
 - D Minnesota Department of Health.

- 2 A licensed school nurse may delegate to others if these areas of competency are considered: safety, staffing, schooling, and:
 - A Supervision.
 - B Supplies.
 - C Students.
 - D Security.

- 3 As a school health paraprofessional, you would:
 - A Maintain the health room.
 - B Participate in screening programs.
 - C Make referrals to licensed school nurse for follow-up.
 - D All of the above.

- 4 Communication can be verbal and nonverbal. Examples of nonverbal communication are:
 - A Writing.
 - B Gestures.
 - C Eye contact.
 - D All of the above.

- 5 As the school health paraprofessional, you can communicate an attitude of caring by:
 - A Ignoring the student.
 - B Sitting and listening to students.
 - C No eye contact with student
 - D Stand with arms folded.

- 6 The way we each perceive a situation and act on it can depend on our:

- A Value system.
 - B Culture.
 - C Education and experience.
 - D All of the above.
- 7 There are steps in solving problems. One step that is NOT used to solve problems is:
- A Identify and describe the problem.
 - B Determine the cause of the problem.
 - C Ignore the situation.
 - D Evaluate the results.
- 8 Team members work together. One barrier to team communication is:
- A My point of view is right.
 - B We listen and accept each other.
 - C My knowledge of pertinent information is shared.
 - D We are creative in problem-solving.
- 9 There are various individual plans developed for those with disabilities. Three examples are listed below. Circle which one is not:
- A IEP
 - B IHP
 - C IDS
 - D IFSP
- 10 At the team meeting, the team leader asks for the school health paraprofessional's opinion of the student's progress. This is an example of:
- A Harmonizing.
 - B Gate keeping.
 - C Evaluating.
 - D Aggressing.

True or False: In the blank provided, write "T" for a true statement and "F" for a false statement.

- 11 The professional nurse is authorized to delegate independent nursing functions to other nursing personnel.
- 12 As a school health paraprofessional, I am responsible only to the Special Education Director.

- 13 The school nurse is responsible for training the school health paraprofessional on site.
- 14 Confidentiality is not sharing information about a student in the lounge.
- 15 Silence is a form of communication.
- 16 When the school nurse delegates tasks to the school health paraprofessional, the responsibilities lie with the school health paraprofessional.
- 17 It isn't necessary that a paraprofessional be involved in writing individual plans for the student he or she works with.
- 18 There are three functions of a team: task functions, maintenance functions, and anti group functions.
- 19 Blocking is an example of the anti-group function.
- 20 To be an effective team member, you need to have vague communication skills.

Quiz Unit 3

Multiple Choice: Pick the letter that corresponds with the choice that best completes each statement.

- 1 Mary has allergies to dust and mold. She would want to stay away from:
 - A Writing with chalk.
 - B Eating tomatoes.
 - C Playing on swings.
 - D Wearing perfumes.

- 2 Cerebral palsy is caused by damage to the brain:
 - A By a blow to the head.
 - B From a high fever.
 - C Drinking alcohol.
 - D From the birth process.

- 3 E/BD can be caused by four main factors. Which is **not** a factor?
 - A Family
 - B Biological
 - C Diet
 - D School

- 4 Jennie was in a car accident, resulting in a TBI. You could expect to see physical impairments such as:
 - A Heart murmur.
 - B Paraplegia.
 - C Indigestion.
 - D High blood sugar.

- 5 TB is still an active contagious disease. It is a disease that generally involves the:
 - A Brain.
 - B Eyes.
 - C Stomach.
 - D Lungs.

- 6 Warning sign of suicide include:
 - A Giving away cherished objects.
 - B Interest in guns or medication.

Unit 3: Answers

1 A	11 F
2 D	12 F
3 C	13 T
4 B	14 F
5 D	15 F
6 D	16 F
7 C	17 T
8 A	18 T
9 B	19 F
10 C	20 T

- C Writing about death.
 - D All of the above.
- 7 There are several physical problems associated with eating disorders. Which one is **not**?
- A Muscle cramps.
 - B Chronic constipation.
 - C High blood sugar.
 - D Cessation of menstruation.
- 8 Listed are three safety precautions a student with hemophilia should follow. Select the **incorrect response**.
- A Carrying heavy articles over 30 lbs.
 - B Wear seat belt in the car.
 - C Wear helmet while biking.
 - D Using safety shield on handsaw.
- 9 Lupus is a chronic disease which affects the skin, joints, blood and
- A Stomach.
 - B Kidneys.
 - C Brain.
 - D Spinal cord.
- 10 A child with type I diabetes needs to balance their insulin with their food intake and:
- A Daily vitamins.
 - B Study habits.
 - C Amount of exercise.
 - D Amount of liquids consumed.

True or False: In the blank provided, write "T" for a true statement and "F" for a false statement.

- 11 Students with ADHD have neat, carefully prepared school work.
- 12 An acute attack of asthma will last your lifetime.
- 13 There are two main types of diabetes – insulin-dependent (type I) and non-insulin dependent (type II).
- 14 A person who has spina bifida will walk with a normal gait.
- 15 The most common childhood cancer is brain tumors.

- 16 A common first aid procedure for someone having a seizure is to put a tongue depressor in their mouth.
- 17 Symptoms of CF are salty-tasting skin, coughing, wheezing, excessive appetite, poor weight gain, and smelly stools.
- 18 The most common method to check your sugar level is with a glucose monitor.
- 19 A child with congenital heart disease develops this disease at nine months of age.
- 20 Tourette syndrome may be mistaken as ADHD.

Unit 4: Answers

- | | |
|------|------|
| 1 D | 11 T |
| 2 C | 12 F |
| 3 B | 13 T |
| 4 A | 14 F |
| 5 D | 15 F |
| 6 D | 16 T |
| 7 C | 17 T |
| 8 A | 18 F |
| 9 B | 19 T |
| 10 A | 20 T |

Quiz Unit 4

Multiple Choice: Pick the letter that corresponds with the choice that best complete each statement.

- 1 Methods to practice infection control are:
 - A wash your hands.
 - B wear gloves.
 - C work from clean to dirty.
 - D all of the above.

- 2 A major concern for students with diarrhea is dehydration. Signs of dehydration include **all but one** of the following:
 - A Dry skin.
 - B Crying without tears.
 - C Moist, sweaty skin.
 - D Decreased urination.

- 3 Vital signs include all **except**:
 - A Temperature.
 - B Weight.
 - C Pulse.
 - D Respiration.

- 4 Devices used to aid mobility include all of the following **except**:
 - A Catheter.
 - B Crutches.
 - C Walker.
 - D Wheelchair.

- 5 James receives oxygen. Safety precautions you need to remember are:
 - A Keep oxygen away from heat.
 - B Store oxygen tank upright.
 - C Use a humidifier.
 - D All of the above.

- 6 Other methods of receiving nutrition besides eating are listed below. Which method is incorrect?
 - A NG tube.

- B Gastrostomy.
- C IV.
- D Colostomy.

- 7 The six "R's" include right person, right medication, right dose, and the following **except** right:
 - A Route
 - B Record
 - C Doctor
 - D Time

- 8 John needs to receive his antibiotic at noon for ten days. Which method are you as school health paraprofessional not allowed to use?
 - A Injection
 - B Oral pill
 - C Oral liquid
 - D Ointment

- 9 The school health paraprofessionals administer medication when authorized by:
 - A Psychologist
 - B Licensed school nurse
 - C Teacher
 - D Superintendent

- 10 Medically fragile students:
 - A Include those with a variety of serious physical health needs
 - B Receive this injection at home
 - C Are not able to develop friendships
 - D Must return to the hospital frequently

True or False: In the blank provided, write "T" if the statement is true and "F" if the statement is false.

- 11 Body mechanics are essential for you when transferring a student from wheelchair to a desk chair.
- 12 A person with a tracheostomy can speak without assistance.
- 13 Before administering any medications, the policies of the school district must be reviewed and followed.
- 14 Encourage students who need assistance with eating to hurry so they can go to recess.

- 15 As a school health paraprofessional, you are allowed to administer medications at any time.
- 16 Wash hands and wear gloves when diapering.
- 17 To transfer a dependent person, use a transfer belt.
- 18 Medication may be kept in your unlocked desk drawer.
- 19 Hand washing is the single most effective way to prevent the spread of infections.
- 20 Students with disabilities often need a longer time to complete a task.



Introduction

An Introduction to the Series

This series should be useful to paraprofessionals and paraeducators in education as well as direct service staff in community agencies in preparing for a career or in upgrading skills while already employed. Skills needed by individuals working under a variety of titles are often similar. Our focus is on those individuals working in education, but most of the information contained in this series is appropriate for others; please feel free to adapt it where needed.

The Need for Today's Paraprofessionals

The need for paraprofessionals to work with persons who have disabilities has been growing in recent years. Increasing numbers of persons with a range of disabilities are now living in small residential settings in our communities, attending regular classes in neighborhood schools, holding jobs in local businesses, and participating in community recreation and social activities. There is a great need for paraprofessionals to provide the services and supports these individual need for community living.

By employing paraprofessionals, services for persons with disabilities are able to expand and improve the quality of assistance they provide. Some of the benefits paraprofessionals offer service agencies and consumers are:

- Expanded learning opportunities for persons with disabilities.
- More individualized attention and instruction.
- Increased opportunities for individuals with disabilities to observe and learn appropriate behaviors.
- Increased planning time for educators, supervisors, and others.
- Improved staff morale.
- Better monitoring and evaluation of persons with disabilities.
- Greater consistency in services.
- Improved parent-school relationships.
- Greater involvement of persons with disabilities in education and other settings in the community at large.
- Transportation assistance for individuals with disabilities.
- Vocational skill development for individuals with disabilities.

The Role of Today's Paraprofessional

Paraprofessionals who work with individuals with disabilities have a variety of roles and definitions, depending on the environment in which they work. The Minnesota Department of Education (MN 3525.0200, Subp. 9b) definition states that a program assistant or pupil support assistant provides services to students only

under the direct guidance and direction of a regular or special education teacher or related provider, and those services must be:

- To enhance the instruction provided by the teacher or related staff in academic instruction, physical or behavior management programs, transition, and other integrated activities.
- To supplement instructional activities or to provide extended practice in instances in which the support assistant has had training from a special education or related services staff, and continues to receive ongoing direction and support from a special education teacher.

From the National Resource Center for Paraprofessionals in Special Education and Related Services (City University of New York) comes this definition of a paraprofessional:

A paraprofessional is an employee:

- Whose position is either instructional in nature or who delivers other direct services to individuals and/or their parents.
- Who works under the supervision of a professional staff member who is responsible for the overall management of the program area including the design, implementation and evaluation of instructional programs and the individual's progress.

Paraprofessionals provide services in the following areas:

- Educational programs
- Physical therapy
- Occupational therapy
- Speech therapy
- Recreation programs
- Early intervention and preschool programs
- Social work/case management
- Parent training/child-find programs
- Vocational training programs and job coaching
- Community programs
- Transition

Paraprofessionals are typically different from professionals in the amount of education, certification required for the job, degree of responsibility, and extent of supervision required.

Because the support of paraprofessionals is so essential to the success of individuals with disabilities, this series is dedicated to improving and enhancing skills for paraprofessionals.

About the Series

Whether you have years of experience working with persons who have disabilities or are just beginning, there are probably many

questions you have about the role of a paraprofessional. Some concerns and questions will be very specific to your work setting, while others will be more general. This series, *Strategies for Paraprofessionals Who Support Individuals with Disabilities*, will cover both.

This curriculum is primarily for paraprofessionals who are (or will be) working in educational settings (i.e., special and general education). It will, however, also be useful for those in direct service settings, such as vocational programs and residential settings.

The *Strategies for Paraprofessionals Who Support Individuals with Disabilities* curriculum has four general, or core, training modules and three specialized modules. The core modules, designed for all paraprofessionals, are:

- Module 1: The Paraprofessional: An Introduction
- Module 2: Providing Cross-Cultural Support Services to Individuals with Disabilities and Their Families
- Module 3: Promoting Self Advocacy and Facilitating Friendships and Socialization Skills for Individuals with Disabilities
- Module 4: Positive Behavior Strategies for Paraprofessionals

The three specialized modules that address competencies needed in specific types of service settings are:

- Module 5: Early Childhood: The Role of the Paraprofessional
- Module 6: Working with Individuals Who Are Medically Fragile or Have Physical Disabilities
- Module 7: Transition: The Role of the Paraprofessional

Each module is designed to stand alone, so you may select any one that best meets your needs. However, it's recommended that everyone begin with Module 1 because it provides a basic framework for work as a paraprofessional and for the material covered in all the other modules.

The training you are about to begin will not only address the current reality for paraprofessionals working with individuals with disabilities, but more importantly, the challenges for the future in your career as a paraprofessional. Paraprofessionals aren't expected to have a total understanding of all the concepts in these modules, but the paraprofessional who has a working knowledge of these core concepts will be most effective.

Guiding Principles

Each module emphasizes six basic guiding principles for paraprofessionals working with individuals with disabilities. Those principles include:

- The individual with a disability is the ultimate locus of control and is the most important member in the decision making process.

- The family is the other primary locus of control. Family involvement is essential in any decision making process.
- The team concept is essential in setting up a plan with an individual. This team includes the individual, the family, and all those working with the individual, including the paraprofessional. The paraprofessional is an essential link between what is and what can be for the individual. The best follow-through on any plan comes from teamwork.
- The community should be the basis for all training, as much as possible. This means that, whether offering real-life examples in the classroom or working in real life situations in the community, the focus must be on the most natural setting and support possible. This is essential so the individual can make connections between what is being learned on a daily basis and the real world. This will help the individual generalize the experience to similar situations in his or her life.
- Inclusion is the goal. This means that individuals with disabilities should be included in the mainstream of society – work, school, and recreation. Devotion to such a model will create the most positive results for the individuals and society as a whole. Inclusion suggests that we can and will all benefit by learning to work and live side by side with each other.
- The most effective paraprofessional will be the individual who has a good self-esteem and is able to be assertive. The assertive paraprofessional is able to ask for support and guidance from staff.

About You: The Adult Learner

We know that the adult learner learns differently than younger learners. This training reflects that understanding. In *Strategies for Paraprofessionals Who Support Individuals with Disabilities* we respect these principles about you, the adult learner:

- You are capable and eager to learn new information.
- You have voluntarily given your consent to become a part of this training, and are spending valuable time and money in order to participate.
- You have a rich range of experiences. Therefore you learn best when new information is built upon your past knowledge and experiences. That's why we will do exercises to help you synthesize the old and new information together.
- You come to a new learning situation as a self-reliant learner who has a good idea of how you want and expect to learn.
- Your willingness to learn is based on a combination of outside forces (family, kids, job, etc.) and inside forces (your anxiety, excitement, fears, etc.). All these factors are going to affect your feelings about learning.

- You come into new learning with your own agenda. You know what you want to get out of the training.
- You have set aside time and reorganized priorities to make this learning part of your already-busy life.
- You expect and genuinely appreciate a facilitator or instructor who is well-informed and well-prepared.
- You need to get actively involved in the learning exercises to get the most out of this curriculum.
- You want to apply what you learn to your own situations. That's when it has real meaning for you.
- You need a safe, comfortable environment in which to learn.
- You want to establish networks with others who are also interested in paraprofessional skills.

Because of these facts about you, trainers will:

- Review and ask questions about what you know.
- Respect and view you as a resource.
- Create a comfortable environment.
- Expect you to take responsibility for your own learning.
- Plan opportunities to practice new skills during class.
- Give examples of how to apply information.
- Use a variety of types of instruction.
- Provide ways to evaluate training.
- Use alternate methods to help you understand.
- Give information in a logical sequence.
- Give time for you to share your experiences.
- Give you the chance to get know other paraprofessionals.

After the Training

You will leave this training with more information about paraprofessionals than you had when you started. It's important to remember that no matter how much knowledge you have about your job, the individuals you work with are your greatest trainers. Each one is unique and has his or her own interests and needs. The greatest responsibility you have is to listen to those interests and needs, remember what you have learned, ask what is needed, and use that information in your working relationship and responsibilities.

Therefore, use this training as a basis and build your skills from this point, drawing upon each setting and individual. Whether client, student, teacher, supervisor, principal, director, or superintendent, you will learn from each. With each setting and situation your confidence, ability, and skills will continue to grow. Remember, this training is only as good as the degree to which you use what you learn; seek assistance so you can "do what you know."

Chapter One

1

Changing Roles of Education Related to Students with Disabilities

- 1 Introduction**
- 2 Section 1: Background Information on Health
Impairments in Educational Settings**
- 7 Summary**
- 7 Questions to Ponder**

Introduction

In this module you will read about and discuss many types of medically fragile conditions and physical disabilities. Keep in mind that this module doesn't strive to make the paraprofessional an expert in any area, but instead aims to give an overview of the most common disabling conditions found by the paraprofessional, and basic techniques and care that the paraprofessional – with nursing supervision – should provide.

Advances in health care technology procedures have dramatically increased the survival rates of low birth weight infants, children with chronic illnesses or congenital abnormalities, and survivors of trauma. These survival rates have led to increases in children with health care needs, including those requiring technology assistance.

Before the 1980s, children with long-term special health needs were cared for in hospitals. Today, child advocates support normalization for children with special health care needs, including school attendance in the least restrictive environment. This has changed the school profile and invited new challenges for school staff and increased, in many cases, the responsibilities of the school health care paraprofessional. There are several reasons for these changes. First is the legislation at the state and federal level to deinstitutionalize individuals with disabilities so they might have as normal an environment to live and grow in as possible. Second is that it's much more cost-effective to have individuals with disabilities mainstreamed into society rather than segregated in state institutions. A third reason the changes have taken place is that there has been tremendous pressure from parent and advocacy groups to "normalize" the environments of individuals with disabilities. These advocacy groups believe that individuals with disabilities should be at home and in their neighborhoods whenever possible.

Assigning roles and responsibilities for carrying out special health care procedures has become an issue because of the growing numbers of students with disabilities and special health care needs who are entering school and work environments. Many settings have no set procedures or responsibilities assigned for the often delicate and unique needs of these individuals; thus, the need exists to clarify such staff roles. This module will give background information to paraprofessionals who may find themselves responsible for meeting some or all of those unique individual health care issues. This module only attempts to address these topics in a general way. To really explore all the areas covered here would require much more time and space than allowed here. It's also felt that knowledge beyond this basic background information should be reserved for specific supervision by the nurse on staff and under specific topical training.

Discussion

Introduce the unit by discussing the issues and challenges in this introductory session. Many of the students may already be working in situations where they serve individuals with medically fragile conditions. Have them discuss their feelings about and trials and triumphs with these experiences. Ask students what they see as most important to learn from this module.

Section 1

Background Information on Health Impairments in Educational Settings

Discussion 1

Students will read this section as supplemental background information on the increased numbers of individuals with disabilities and special health care needs entering schools today. Discuss its contents with the students. Relate these new challenges to their work in schools either as a health paraprofessional or a special education paraprofessional working one-on-one with an individual who may have special health needs.

Discussion 2

Although many of the needs and concerns of individuals with medically fragile conditions are the same as or similar to those of individuals with physical disabilities, special concerns might prevail with an individual with a physical disability. Ask students to discuss key issues and challenges in their work environment (or one in which they hope to work) for individuals with physical disabilities.

Physical Disability

According to Public Law 94-142 (now IDEA) the definition of a physical disability is:

A disorder where severe physical impairment adversely affects the individual's performance. One of the most common causes of physical disability is damage to or the breakdown of the central nervous system – the brain or spinal cord. Individuals with physical disabilities may have mental retardation, learning disabilities, emotional disturbances, speech or language disorders, or special gifts and talents.

"Orthopedic" or "physical" disabilities describe medical or structural conditions serious enough to disrupt the individual's development and require special attention in school, work, or residential settings. Typical examples of orthopedic or physical problems include disabilities present at birth (such as missing limbs, spina bifida, etc.), as well as physical problems resulting from other causes (such as contractures caused by burns or fractures, etc.). In addition, neurological problems may be included in this category.

Health impairments – such as asthma, cardiac conditions, sickle cell anemia, epilepsy, and leukemia – may result in limited strength, vitality, alertness, and affect one's education and work.

One half of one percent (.5%) is the figure usually cited in estimates of school-aged individuals with physical or health impairments. Cerebral palsy accounts for a large part of this percentage, followed by spina bifida.

Characteristics

Physical disabilities can produce a variety of characteristics. Children may experience a wide range of restrictions on their activity, from little or none to a complete restructuring of daily life. The most severely affected individuals may require intensive medical and educational help for which the nurse and health paraprofessional may be called upon to assist. Physical challenges may interfere with an individual's motor functioning, communication, learning skills, or social development.

General Characteristics of Physical Disabilities

Please remember that these are possible characteristics to a very broad category of disability. Not everyone with physical disabilities have all these characteristics. The individual may:

- Have below average motor skills.
- Have jerky or shaky movements.
- Have poor self-esteem in relation to disability challenges.
- Have poor coordination or muscular control.
- Have problems developing good relationships with others.
- Walk slowly or have limited mobility.
- Move around to redistribute weight, if in a wheelchair.

Educational Implications

The contributions of such related services as physical, occupational, and speech and language therapy are often central to the education of individuals with physical disabilities. The greatest progress is achieved when therapy suggestions are consistently applied in the individual's home as well as in school. This carry-over strengthens appropriate feeding, positioning, and language stimulation patterns.

Architectural factors must be considered. Section 504 of the Rehabilitation Act of 1973 requires that programs receiving federal funds make their programs accessible (see Chapter Four for more detail). This could mean structural changes (e.g., adding elevators or ramps) or schedule or location changes (e.g., offering a course on the ground floor). Sometimes the nature of the individual's disability requires changes in school equipment or curriculum. In the same way an individual's placement should be the least restrictive one appropriate for him or her, the day-to-day school pattern also should be as "normal" as possible.

Physical disabilities can have profound effects on one's emotional and social development. To promote growth, parents and teachers should avoid overprotection and encourage individuals to take risks within limits of safety and health. Teachers and peers should also understand that, although individuals with physical disabilities and health impairments may be physically disabled, they are more like their peers than different from them.

Technology holds great promise for making the life of individuals with a disability more "normal". Computerized devices, for example, can help non-vocal, severely physically involved individuals communicate, perhaps for the first time.

Students who require recurrent or long-term hospital care for their condition may need services such as tutoring or home bound instruction to keep up with their academic requirements. Depending upon the nature and severity of the condition, counseling for the family may be helpful.

Discussion 3

After the description of characteristics, emphasize that this isn't an all-inclusive list of characteristics. Some individuals with a given disability may have some, none, or all of these characteristics.

Discussion 4

Ask students to share their experiences in working with individuals who have physical disabilities. Students will use the "Additional Tips" to add the ideas of others in the group.

Tips for Working with Individuals with Physical Disabilities

- Make sure working or teaching areas are physically accessible.
- Arrange the environment, if necessary, to accommodate the individual's wheelchair or other mobility needs.
- Consider emergency evacuation and what alternatives would be necessary for the individual. Then acquaint the individual with the procedure he or she should follow.
- Don't isolate the individual in a seating arrangement because of mobility needs, but include the individual into the setting while still giving him or her accessible seating.
- Support the need of the individual to have the necessary time to get from one location to another without the hassle of crowds, whenever possible.
- Arrange a peer partner for the individual in situations where it would be the easiest and most logical support.
- Encourage the accommodation of extra time for the individual to complete written tasks.
- Work out necessary adaptations in the setting with the individual and supervisor or teacher to meet specific needs.
- Support accommodations such as giving answers into a tape recorder or giving answers if he or she cannot write.
- Be honest with the others in the setting by letting them know how they can and cannot help the individual who is physically disabled.
- Additional tips:

Adapted from a fact sheet produced by National Information Center for Children and Youth with Disabilities: Washington, DC.

Other Health Impairments

Health impaired is a term commonly used for someone who has chronic health challenges or is medically fragile. Health impaired, as defined by Public Law 94-142 (now IDEA), refers to an individual who has limited strength, vitality or alertness, due to chronic or acute health problems such as heart condition, tuberculosis, rheumatic fever, nephritis, asthma, sickle cell anemia, hemophilia, epilepsy, lead poisoning, leukemia, cancer, diabetes, or acquired immune deficiency syndrome (AIDS), which adversely affects an individual's ability to perform.

Characteristics of People with Health Impairments

Remember that these are possible characteristics, but, of course, not all people with health impairments have all of these characteristics. This is just a guideline to give you an understanding of the possible characteristics involved. The individual may:

- Display such defense mechanisms as denial, withdrawal, depression, anxiety, hostility.
- Show over-dependence on parents and family members.
- Have economic difficulty due to extended illness.
- Have transportation difficulty.
- Appear to have limited friends.
- Have poor attendance (health related).
- Appear inattentive or listless.
- Tire easily.
- Appear to have low self-esteem.
- Need to rest frequently.
- Have limited mobility depending on his or her illness.

Tips for Working with Individuals with Health Impairments

- Be part of the planning team or ask your supervisor about any health issues you need to be aware of when working with an individual.
- Offer suggestions and observations in planning for the individual to help accommodate absences. This way the individual can attempt to keep up, even if there are extended periods at home or in the hospital.
- Understand that the individual's expectations and reasons for attending and participating in your setting may be different from others. Participate in sessions that ask the individual and his or her family about personal and family goals for attending your setting.
- Offer the individual an atmosphere of acceptance: make arrangements if she or he needs frequent breaks to rest.
- Arrange the environment in a way that best accommodates access to whatever facilities he or she needs (bathroom, hallways, work station, etc.).
- Find out what special equipment is needed to provide reasonable accommodations. Work with the individual's planning team and family.
- Allow individual to work at his or her own pace.
- Make audio or video tapes of activities so the individual can use these when absent.
- Help to determine what the reasonable accommodations are

Discussion 5

After the description of characteristics, emphasize to the students that this isn't an all-inclusive list of characteristics. Some individuals with this disability may have some, none, or all of these characteristics.

Activity 1

Ask students to share their experiences in working with individuals who are health impaired. Students will use the "Additional Tips" to add the ideas of others in the group.

Activity 2

Interview a student with a chronic illness and/or his or her family in your community. Formulate a set of questions you would ask to address issues families and individuals face in work and/or school settings. Relate these issues to the paraprofessional's role and ask the individual and/or family members what support they feel paraprofessionals should be to them. Write these responses down and be prepared to share them with the class.

Activity 3

This form will be completed by the LSN during student/family conference with the nurse. The SHP needs to be aware of the responses. If the SHP has questions or needs more information, he or she should be referred to the LSN. The SHP may gather information from the student or family with direction from the LSN.

for the individual encourage the individual to practice using these accommodations.

- Additional tips:

Gathering Health Needs Information

The school nurse should have had an opportunity to assess a student and his or her family's needs prior to or immediately at school entrance. Such information is used by all school staff who work with students.

The following is a sample form which may be helpful to use when meeting with individuals for the first time to determine their health needs in your environment. It contains the kind of information you may want to share with the school nurse. You may also want to use this in addition to the health information collected on the health record.

Student name _____ Date _____

School/work site _____

Grade/Age _____ Advisor _____

- 1 What is the nature of your medical condition/disability?

- 2 How long have you had this condition?

- 3 How long do you feel you will need support from our office for specific needs you may have?

- 4 Do you know how to ask for what you need?

- 5 What specifically do you need help with during the school/work day?

6 What equipment do you use or need?

7 Do you need assistance with them during the day? If so, what type of assistance? When?

8 Do you have any special concerns or personal needs that I should know about and can support you in? (Is there anything else I should know?)

9 Other comments or observations (*Date your comments.*)

Activity 7

Discuss with the students the importance of understanding where the individual's "coming from" emotionally and physically when they come into the health office for help and support. Explain that this is important for everyone at all ages. Understanding the basics about the disability areas discussed in this module, as well as attaining a level of sensitivity, is essential for best meeting the needs of the individuals. Students will discuss this point and add to the variables listed below during discussion.

Summary

Children who have physical disabilities or other chronic health conditions are attending school, and they participate like their other classmates do in their regular classroom. Sometimes these children have physical needs that they need assistance to perform. Definitions have been established to differentiate these students in order that their individual needs can be met.

Questions to Ponder

- What's your experience in working with students who have physical disabilities or other chronic health conditions?
- How would you differentiate between students with physical disabilities and students with other chronic health conditions?
- What implications of IDEA have you seen or experienced in your school?

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Chapter Two

Demographics & Disabilities

- 9 Introduction
- 9 Section 1 National Demographics Related to Disability
- 11 Summary
- 11 Questions to Ponder

Introduction

In preparing to work with individuals with disabilities in general, and especially those with special care needs, it's helpful to have background data on just how many people in the United States have disabilities. It's also helpful information to know how many people with disabilities are working in communities. This information adds to your perspective about the value of supporting individuals with disabilities in your school, work, or residential setting. It lends credibility to value of supporting the preparation of individuals with disabilities for post-secondary schools and work settings. The following facts are presented to you as background information from a national perspective.

Section 1

National Demographics Related to Disability

According to the Americans with Disabilities Act of 1990, there are 43 million Americans with disabilities.

Although there are many ways of calculating these numbers, the President's Committee has calculated the following data which was published by The National Center for Medical Rehabilitation Research in "The Scope of Physical Disability in America - Populations Served":

- People with hearing impairments:
22 million, including 2 million who are deaf
- People who are totally blind:
120,000
- People who are legally blind:
60,000
- People with epilepsy:
2 million (Note that four out of five people with epilepsy don't have seizures because they take medication.)
- People who are partially or completely paralyzed:
1.2 million
- People who use wheelchairs:
1 million
- People with developmental disabilities such as cerebral palsy and mental retardation:
9.2 million

Discussion 1

Read and discuss with students the facts and attitudes reflected in this report. Ask students to express their opinions and feelings about individuals with disabilities in the work force. Explain how special conditions for health issues are dealt with in work environments. Remind students that under federal law, (Section 504 of the Rehabilitation Act and the ADA) individuals with disabilities are entitled to "reasonable accommodations" on the job as well as in schools. For example, it might be an appropriate accommodation for an individual with a medically fragile condition or a physical disability to have an attendant on the job to support him or her.

Activity 1

According to the 1990 census, there are 249.6 million people in the U.S.; 43 million, or roughly 17 percent, have disabilities. To illustrate this relationship, split the class into groups of 17 and 83% each.

Activity 2

Refer students to Appendix S, *Estimated Prevalence of the Major Uncommon Diseases and Conditions in Children*. This can be made into an overhead to facilitate class discussion.

- People with speech impairments:
2.1 million
- People with mental retardation:
2–2.5 million people. Nine out of ten people with mental retardation have mild mental retardation.
- According to the National Institute on Mental Health, there are five million people with mental illness.

Work Force Data on Individuals with Disabilities

In 1989, the Census Bureau reported the following work-force data about persons with disabilities in the work-force in a report entitled *Labor Force Status and Other Characteristics of Persons with a Work Disability: 1981–1988*.

- 13.4 million people ages 16 to 64 report a work-related disability. That's 8.6% or about one in every twelve Americans with disabilities.
- 31.6% of people with disabilities work or actively seek work.
- 78.6% of Americans without disabilities work or actively seek work.
- Participation in the labor force of men with disabilities (working or actively seeking work) has dropped from 41.9% in 1981 to 35.7% in 1989. However, among women with disabilities, it has risen to 27.5% from 23.7%.
- One in three severely disabled adults is black or of Hispanic origin, compared to just over one in five in 1982.
- Adults with disabilities are almost four times as likely as are non-disabled adults to have less than a ninth grade education.
- According to a Harris Poll taken in 1986, two out of three people with disabilities aren't working. And of those, two out of three want to work.

Reactions of Employers to Workers with Disabilities

The following is data from over nine hundred managers interviewed by the Harris Poll who have people with disabilities working for them:

- Nineteen out of twenty managers give employees with disabilities a "good" or "excellent" rating on their job performance. They say employees with disabilities work as hard or harder than employees who don't have disabilities.
- Thirty-nine percent of line managers rate employees with disabilities as better on attendance and punctuality than non-disabled employees, and forty percent rate them about the same.
- The average cost of hiring a person with disabilities is the same

as hiring a person without a disability, according to three quarters of the employers surveyed.

- Only 43% of EEO officers say that their companies have hired people with disabilities.
- Three out of every four managers say that people with disabilities often encounter discrimination from employers.

This information was taken from a report written by the President's Committee on Employment of People with Disabilities: Washington, DC.

Summary

With the onset of the American with Disabilities Act (ADA) and IDEA, people with disabilities are expecting reasonable accommodations at school, work, recreation, and employment and inclusion in classrooms. In examining demographics it can be demonstrated that many people live with disabilities in the U.S. – a number that is increasing – and that people with disabilities are productive, capable citizens.

Questions to Ponder

- What's your experience in working with people who have disabilities or a chronic health condition?
- If you have a disability, what expectations would you have for education, recreation, or work?
- How do the ADA and IDEA make a difference in your life?

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Chapter Three

Inclusive Language

- 13* Introduction
- 13* Section 1 Etiquette & Disabilities
- 16* Section 2 Inclusive Language
- 17* Summary
- 17* Questions to Ponder

Introduction

In your position as a health paraprofessional or general paraprofessional, you will probably be put into situations with little or no explanation about what the appropriate etiquette is for dealing with an individual's unique disability needs. These are brief tips and ideas for using appropriate etiquette with people with disabilities which can help prepare you for those occasions.

Section 1

Etiquette and Disabilities

The best course of action for the paraprofessional is always to ask individuals what they need from you or what you can do to assist them. Never assume you know what's best for the individual without first asking: doing so would take away the individual's rights and integrity. Some general tips to provide you with some background suggestions are listed below.

How do we learn to be comfortable around people who are different from us? How do we know the right thing to do to be helpful, but not patronizing or condescending? For many of us, our first exposure to disabilities came through a family experience, either through permanent or temporary disability, during or after an illness. It has been said that aging, in and of itself, is synonymous with disability: as we age, we begin to confront the fragility of life. In this sense, most of us will come to terms with our own disabilities, our own fragility, at some point. It isn't uncommon to feel uneasy around a person with a disability especially when there has been not prior experience or awareness.

Whatever the exposure to persons with disabilities, one's comfort can be increased by an awareness of what is and isn't expected or appreciated. The following points are designed to increase one's awareness and comfort with persons with disabilities.

General Suggestions

- Remember that people with disabilities are more "similar to" than "different from" other people. Build on interests the individual shares with others without focusing on differences.
- Don't develop preconceived notions about what the individual can or can't do. Be as friendly as you would be with any other person. Let the individual take the initiative to explain the disability, limitations, and accommodations or modifications needed; if the individual doesn't take the initiative, then you should ask.

Activity 1

Role play several situations in which the students assist a person who has a physical disability. Have one student play the part of the individual with the disability and one student act out the appropriate procedure to assist. Use different student for each role play situation. Examples of role play scenes might be:

Situation: A person has cerebral palsy and is in a wheelchair. The person is asking for assistance but speaks very unclearly. The assisting person needs to ask for clarification several times before he or she understands that the individual is asking for help to go to the restroom.

Situation: An individual who is blind is in a demonstration group where everything is typically given visually. The instructor/trainer asks the person with the visual impairment what sort of help he or she will need to follow the demonstration. The individual says he or she needs the trainer to verbally describe all that is being done and he or she can transcribe in on a braille as the demonstration is given. The individual also says he or she will need to be "walked through" the floor plan of the room. The trainer practices doing this with the individual.

- Be consistent in what behavior you expect of everyone with whom you work. Don't accept inappropriate behavior from someone with a disability just because he or she has a disability. This will only make the person less self-sufficient because socially inappropriate behaviors would not be accepted in work or social settings.
- Always ask if the individual needs assistance. Don't assume he or she needs help and jump in. The best rule of thumb is to let the individual know they can ask and receive help at any time and then let the individual take the lead.
- Be patient. Let the individual learn and progress at his or her own rate. However frustrated you as the paraprofessional become, it probably doesn't hold a candle to the frustration experienced by the individual with a disability.
- Let the person with a disability take risks: that's the best way to learn about personal potential. Be sure safety precautions have been taken, but don't over-protect the individual.
- Be a role model for non-disabled people by showing appropriate behavior toward the individuals you work with who have disabilities.
- When in public, if a child asks questions about a person they see with disabilities, answer directly and promptly. The person with the disability may often be willing to answer the question for the child.

Specific Suggestions for Individuals with Any Disability

- If the person doesn't speak clearly, don't be afraid to ask the him or her to repeat, even several times if necessary.
- Don't be afraid to laugh with the person.
- Give help only when it's requested. Sometimes offering (if the individual falls, for example) may be appropriate, but never assume assistance is wanted. Let the person explain the specific help he or she needs.
- Don't stare at a person with disabilities but at the same time don't ignore his or her existence.
- Talk directly to the person with the disability, not to the wheelchair or the interpreter, for example.
- Don't patronize a person with a disability by complimenting him or her for something undeserved.
- Don't be afraid to use phrases like "see you later" to a person who is blind or "I haven't heard from you" to a person who is hearing impaired. They usually aren't considered offensive to people with a disability – they may use these phrases too.

Specific Suggestions for Individuals with Visual Impairments

- Identify yourself when entering the presence of a person who is blind.
- When walking with a person who is blind, let the person take your arm and walk a little ahead. Never grab the person's arm.
- Ignore the "service dog" of a person who is visually impaired. The dog is trained to serve and is working. Don't distract the animal.
- Offer information about the immediate surroundings to an individual who is visually impaired. For example, tell the person there's a "construction ahead" sign while walking together, but wait to be asked to offer any further assistance.
- Control noise for a person who is visually impaired because the person compensates for the vision loss by using acute auditory skills.

Specific Suggestions for Individuals with Physical Impairments

- Address the individual in a wheelchair at eye level.
- Don't take control of the individual's wheelchair without first asking or being asked.

Specific Suggestions for Individuals with Hearing Impairments

- Speak directly to an individual who is hard of hearing regardless of whether or not an interpreter is present.
- Ask the individual if he or she understood information given, if you are uncertain or if the person appears unclear.
- Control the environment to keep it as quiet as possible.
- Ask the individual's permission before introducing him or her as hard of hearing.

Section 2

Inclusive Language

Language is a very powerful form of communication. The way people are addressed, written about, and spoken to sends a strong message about how they are valued. In the recent past, the disabilities community has made strong efforts to change the ways people speak and write about persons with disabilities. Putting the *person*

Discussion 1

Discuss how people feel when they hear certain phrases, for example deaf and dumb, or a heart attack victim versus hard of hearing and heart attack survivor. Students will share concerns about use of language to describe. Encourage students to be leaders in setting the trend where they work to use language appropriately. Ask them to "listen" and "read" more carefully in the next few days to see if they notice how language is used to describe persons with disabilities.

Activity 2

Students will read "People First Language" in Appendix A. Discuss appropriate ways to address individuals with disabilities in writing and speaking. Then Students will read the article "Finding Right Words is Still a Big Struggle for 'Disabled People'" in Appendix B. Discuss the strong feelings those from the disabilities community have about use of appropriate language. Ask students to write a paragraph describing a person with a specific disability using "people first" language.

first and not the disability (i.e. a person with epilepsy, not an epileptic person) sends the subtle but strong message that the person is of primary importance, and his or her disability is secondary. Because you may be in a position to write reports about a person's condition or because you may attend meetings in which you are called on to speak about an individual's condition, it is critically important that you be aware of the appropriate language to use. The following is designed to give you some ideas about how to speak and write when referring to people with disabilities.

When speaking and writing about an individual with a disability, *always* put the person first, the disability second. For example one would say,

- "Student with a learning disability,"
- "Person with cerebral palsy,"
- "Individual who uses a wheelchair," or
- "Consumer who has a physical disability."

Use the word *disability* to describe a functional limitation, for example, "Carla has a physical disability which affects her ability to stand for long periods of time" or "Craig has a visual disability and will need special lighting in his work area."

Use the word *handicap* to describe a situation or barrier created by society, the environment, or individuals themselves, for example, "The curb created a handicap for John in his wheelchair," or "The staircase on the outside of the courthouse was a handicap for Norman with his crutches."

Other Tips

- Introduce someone with a disability as you would anyone else. Don't refer to the disability as part of the definition: use his or her name.
- Don't patronize a person with a disability by praising more than would be customary for any student.
- Let the person ask for what she or he needs or describe his or her disability, if and when he or she feels comfortable doing so.
- Say *able-bodied* or *non-disabled* instead of *normal* when referring to someone without a disability as such.
- Avoid pity or pity statements. Avoid terms like *crippled*, *mute*, *deaf and dumb*, or *afflicted*. For example, when talking about someone who has had a heart attack, refer to him or her as a heart attack *survivor* rather than as a heart attack *victim*.
- Don't sensationalize a disability by writing or talking about it if it doesn't bear on the point of the discussion or story.

Summary

How we relate to one another can be easily taken for granted when we don't have a disability or other health conditions. Courtesy and respect are aspects of relationships we expect to receive from and give to others. At times, people with disabilities or chronic health conditions are treated as objects, their needs or wishes are ignored, or are done "to" or "for" rather than "with". It's essential that we all remember to care or work with others as we like to be cared for or worked with. The "golden rule" is the foundation of all our relationships.

Questions to Ponder

- Reflect on a situation you experienced in relation to someone with a disability or chronic health condition. How would you "re-do" the situation if you had the opportunity?
- If your child had a disability or chronic health condition, how would you deal with people who stare or point at the two of you? How would you feel? List strategies you can use to increase your comfort level in relations with students who have disabilities or chronic health conditions.

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Chapter Four

Education & Health Laws

- 19 Introduction
- 19 Section 1 Disability-Related Laws
- 22 Section 2 Laws Relating to Abuse and Neglect
- 24 Summary
- 24 Questions to Ponder

Introduction

Individuals with disabilities and their families are protected under several laws. It's important for individuals with disabilities to understand this and know what laws may apply to them and the rights they have in a particular situation, whether it be employment, school, or living. Therefore, examples of laws have been added to this section on rights so you, as a paraprofessional, have a basic understanding of what some of the laws are affecting the rights of individuals with disabilities.

Section 1 *Disability-Related Laws*

The following are examples of laws that affect individuals with disabilities. This is not meant to be an all-inclusive list; however these are the laws most often referred to in schools and in residential and work settings.

The Americans with Disabilities Act

The most recent law affecting individuals with disabilities is the Americans with Disabilities Act of 1990 (ADA). Read the Fact Sheet from the U.S. Department of Justice (found in Appendix C) to give you a better background of the law and its implications.

Section 504 of the Rehabilitation Act of 1973

As part of the Rehabilitation Act of 1973 (Public Law 93-112) Congress enacted Section 504, the first federal civil rights law protecting the rights of individuals with disabilities. Section 504 provides that, "no otherwise qualified handicapped individual in the United States... shall, solely by reason of... handicap, be excluded from the participation in, be denied the benefits of, or be subjected to discrimination under any program or activity receiving Federal financial assistance."

This law applies to state and local agencies and governments if they receive any federal money.

This law protects any person with a disability who is "otherwise qualified", just like ADA. That means the person with the disability must be able to perform the necessary tasks (with accommodations and modifications if needed) in spite of the disability. This means, if the disability doesn't prevent the individual from doing an adequate performance on the job, he or she is entitled to the job and cannot, under federal law, be denied the job. For example,

Activity 1

Divide the class into three groups and have each read and discuss one of appendices C, D, and E and then relate their discussions to the class as a whole. Students who read the Fact Sheet on ADA in Appendix C should discuss the main points of the law. Students who read Appendix D, "What the ADA Means for People with Developmental Disabilities" can discuss the law's impact on people with all types of disabilities as well as developmental disabilities. Students who read the Section 504 Fact Sheet in Appendix E can discuss how important it is for the individuals with whom they work to understand their rights under Section 504 and other laws.

a person who is mildly retarded who can pass the driver's license test is entitled to be hired to drive the school van because he or she has proven the ability to perform the necessary tasks in spite of the disability.

Section 504 also applied to school. If a student is in need of accommodations or modifications to learn, they are entitled to reasonable accommodations. For example, a person who uses a wheelchair may enroll in a community college and find that the department he or she needs to access doesn't have a ramp or elevator. The school must accommodate that student to access the information. They may do that by relocating the class or lab, or by putting in an elevator or curb cuts. Students who may have learning disabilities are entitled to readers, note-takers, books on tape, or other accommodations to facilitate their learning under Section 504.

Section 504 came long before ADA but has been recently updated and still covers some situations that ADA may not. For further information about Section 504 of the Rehabilitation Act, refer to the Fact Sheet in Appendix D.

Discussion 1

Discuss the rights of parents under IDEA. Ask for student input. Relate the knowledge of these laws and their importance to the ability of individuals and their parents to advocate.

Individuals with Disabilities Education Act (IDEA)

IDEA is a federal law (Public Law 101-476) which was formerly called the Education for All Handicapped Children Act (Public Law 94-142). There are certain minimum standards all states must comply with under IDEA and then each state can add to that compliance with additional statutes. Minnesota Chapter 3525 and Minnesota Laws on Special Education along with IDEA spell out the rights of parents for their children in special education. Some of these rights include the right to:

- To agree or disagree to the school's request to test the child.
- To have the child given a test that is not discriminatory based on race or disability once agreement to assessment is given.
- To receive a written copy of the assessment results.
- To have assessment results explained thoroughly.
- To have an independent evaluation if parents disagree with the school's assessment, in which case the school must pay for the evaluation unless, through a due process hearing, the evaluation given by the school is determined to be appropriate.
- To have parents as equal members of the student's planning team that decides if the student needs special education and if so, to what extent.
- To have someone accompany parents to the Individualized Education Plan (IEP) conference.
- To agree or disagree with the action suggested by the school.

Public Law 99-457 (Part H of IDEA)

This federal law requires schools to serve young children with disabilities beginning at birth. The Individual Family Service Plan (IFSP) is the written document, like the IEP, for this law. In this plan, the needs of children are planned from birth to the age of three. Minnesota has developed an IFSP plan. As of the fall of 1993, all services described in the IFSP (by all the agencies involved) must be implemented.

Material on IDEA adapted with permission from PACER Center, Inc., 4826 Chicago Ave. S, Minneapolis, MN 55417. Telephone: 612/827-2966

Minnesota Rule 3525.2925:**Use of Behavioral Intervention with Pupils**

As another example of Minnesota laws that provide rights to individuals with disabilities, the Behavioral Intervention Procedures for Students with Disabilities is included in this section. This law is specifically directed to rules governing the discipline procedures used with students in school who have disabilities.

In 1989, the Minnesota State Board of Education was directed by the Legislature to adopt rules governing the use of aversive and deprivation procedures for pupils with disabilities. The Board was asked to draft rules which promote the use of positive behavioral interventions, and to ensure that aversive or deprivation procedures, when appropriate for a student, are included in that student's Individual Education Plan (IEP). The rule, which went into effect in January 1992, is intended to encourage the use of positive approaches to modify students' behavior.

Three categories of behavioral interventions are listed in Minnesota's Proposed Permanent Rule for Use of Behavioral Interventions with Pupils Who Have Disabilities. They are *exempted procedures*, *prohibited procedures*, and *regulated procedures*. These three categories are described in detail in Module 5, *Positive Behavior Strategies for Paraprofessionals*.

Each school district is to revise district policies, where necessary, and to provide any necessary staff development to appropriately implement the new rule. Each district should distribute their written discipline policy during IEP meetings, and review common practices in terms of appropriateness for a particular student.

Activity 2

Because so many paraprofessionals in schools deal with behavioral challenges, this section should lend itself to discussion. Encourage students to discuss the pros and cons of this ruling and to relate personal experiences. Remind students that the discipline decisions for students they work with should be directed from their supervisor.

Activity 1

Read and discuss these laws relating to abuse and neglect. Make sure students understand them and their own responsibility for following them.

Section 2

Laws Relating to Abuse and Neglect

It's important to understand some basic laws that apply to your work with individuals who may be subject to abuse and/or neglect. This is just a brief description of some basic information about key laws you should know.

The Vulnerable Adults Act

This is a law in Minnesota that requires all people in licensed occupations, and others, to report abuse and neglect of a group of citizens known as vulnerable adults. These people include individuals with mental and physical disabilities, the elderly, or other adults who cannot protect themselves. The reporting of abuse or neglect of these individuals should be made directly to your supervisor if you suspect any condition that is not healthy or safe for individuals. If you suspect your supervisor or institution of abuse or neglect, you should report incidences to legal authorities.

The Child Abuse Prevention Act

Neglect of children is defined in two places in Minnesota state law. Anyone can report abuse or neglect. However under legal mandate the following people are required to report any suspected incident of child abuse: a professional or the professional's delegate who is engaged in the practice of healing arts, social services, hospital administration, psychological or psychiatric treatment, child care, education, law enforcement, or a member of the clergy. A list of mandated reporters would be physicians, dentists, educators, day care staff, group home staff, therapists, clergy, foster parents, pharmacists, social workers, guardians *ad litem*, and nurses. Paraprofessionals fall into this category and are mandated by state law to report any suspected cases of child abuse. Anyone who reports child abuse or neglect in good faith is immune from any civil or criminal liability. The reporter's name is confidential, accessible only upon consent of the reporter or by court order.

Other Pertinent Minnesota Laws

MS 123.7

This law requires that students be immunized against certain diseases. Student need to show proof that they have had these immunizations when they enter school.

MS 116.75-.83

This law regulates certain contagious diseases by requiring that they be reported to the Minnesota Department of Health. Schools make informal reports about these contagious diseases.

MS 148.17-.285

This is the Nurse Practice Act (see a complete copy of the act in Appendix G). This law describes the relationship of the licensed school nurse (LSN) and other school personnel such as the school health paraprofessional (SHP). The LSN may delegate duties to the school health paraprofessional and is legally responsible for supervising the school health paraprofessional.

MS 123.35

This law states that school districts which have a thousand students or more (preschool through grade twelve) are required to have a licensed school nurse. Schools are to assess the basic health needs of students.

MS 13

This is the Minnesota Government Data Practices Act. This describes how student records are to be kept and what kind of information can be shared about students. This Act states that a release of information must be signed by parent or guardian (or students age eighteen or older) in order to share information about the student.

MS 126.202

This law sets policy for how each school is to establish medication administration. Schools must know these policies and then set their own rules within those policies.

MS 626.556

This is the Maltreatment of Minors Act. It requires that school health paraprofessionals, because they have been delegated by the licensed school nurse, are mandated to report abuse and/or neglect of students.

MS 144.29

Each school must create a permanent public health record to be kept for each child of school age.

Summary

Schools follow numerous federal and state legislative mandates when meeting the educational needs of students. These laws exist to guarantee that all students have the same educational opportunities and the same opportunities to learn. Many of these mandates are especially pertinent to the special education programs, but everyone needs to be aware of them and how these mandates may directly or indirectly effect their experiences at school.

Questions to Ponder

- How does IDEA impact you as you work at school?
- Why are you a mandated reporter?
- The Minnesota statutes relating to health at school are developed from the basic premise that children who are well learn better. How does this idea impact you in your job at school?

5

Chapter Five

Delegation of Responsibilities

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- 25 Section 1 The Role of the School Nurse
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- 35 Questions to Ponder

Introduction

In order for the school health paraprofessional to understand who is responsible for what in the school, it's important to understand the role of the school nurse. She or he will be the paraprofessional's immediate supervisor and the who will give direction and responsibilities to the paraprofessional. Therefore, this section has been added to give you an understanding of the responsibilities of the school nurse.

Section 1

The Role of the School Nurse

Schools now educate and care for individuals with health needs that are extensive in nature, require sophisticated intervention, and often exceed the capabilities of school personnel. These increasing health care demands, coupled with shortages of school nurses, require formal partnerships among all levels of school personnel to provide for the care and well-being of those students with medically fragile conditions. The formation of these health care teams of primarily non-medical personnel raises additional levels of responsibility for the school nurse.

The role of the school nurse in the care of students is to assess the health needs of the child in the school setting and to coordinate with staff, family, physician and community agencies to provide a comprehensive school health program that facilitates the maximum educational opportunity for the individual. This responsibility has escalated dramatically over the past sixteen years with the inclusion of more and more individuals with medically fragile conditions in the school system.

Each state establishes its own health screening criteria for students. These requirements range from minimal to comprehensive. But no matter what the criteria, the school nurse follows certain standards of practice in fulfilling his or her responsibility to the student. Standards of practice for the school nurse have been developed by a task force of organizations, including the National Association of School Nurses (NASN). These standards serve to ensure high quality, comprehensive care for students, as well as to guide the school nurse in daily activities and planning. These standards include the following:

- Application of appropriate theory as the basis for decision making in nursing practice.

Activity 1

Students will read and discuss this section about the role of the school health nurse. Make sure the students understand that their duties should be assigned from the nurse and their activities under her or his direction.

- Establishment and maintenance of a comprehensive school health program.
- Development of individualized health (care) plans.
- Collaboration with other members of the school health team in assessing, planning, implementing and evaluating programs and school health activities.
- Promotion of optimal levels of wellness in students, their families and others through health education.
- Participation in continuing education, peer review, and activities to maintain professional development and excellence.
- Participation with others in the community to provide a continuum of the process to promote healthy life-styles and disease prevention.

Roles and Responsibilities of the School Nurse

The role of the school nurse in working with school personnel is to determine the orientation, education, and training necessary to enable them to participate in a safe and appropriate manner in meeting the health needs of the individuals who has a medically fragile condition. The school nurse is ultimately responsible for training the health paraprofessional on site. School personnel, by and large, have no training in health-related fields. Moreover, most had never anticipated ever having to perform health care procedures when they prepared to become teachers or school employees. Many have also struggled with their anxieties over this additional responsibility as they work to provide high standards of education for students. Since school staff are with the students the majority of the day and are the primary caretakers, it's imperative that all members of the team are trained to participate in appropriate procedures/activities and know when to get the school nurse or secure emergency assistance.

The school nurse has a responsibility to help team members understand both their capabilities as well as their limitations in participating in the health care process. A large part of this understanding needs to be based on a basic knowledge of the state Nurse Practice Act (see Appendix G) regarding delegation. The Nurse Practice Act describes and states that the professional nurse (not the licensed practical nurse) is authorized to delegate independent nursing functions and delegate medical functions to other medical personnel. It clearly states the responsibilities of delegation. Beyond that, the school nurse needs to assess student needs, determine how the staff can participate in meeting those needs, and then develop a training program and resource material to satisfy those goals.

In order to ensure that this is accomplished, the following recommendations were made in 1992 by the American Federation of Teachers to the school:

- Develop a procedure or policy manual and update it regularly.
- Establish a uniform recording system, with standardized forms, for use by all staff.
- Train staff on (appropriate) procedures and routinely assess individuals' ability to perform those procedures safely.
- Keep a documented list of trained staff, when they were trained, and an assessment of their capabilities.
- Develop emergency procedures/evacuation plans and train and evaluate staff in these areas.
- Arrange for or provide inservice training on basic first aid and CPR training.
- Arrange for or provide inservice training on medication administration, when appropriate.
- Arrange for or provide inservice programs on current health issues.
- Arrange for or provide inservice programs on universal precautions and the appropriate disposal of contaminated waste.

Legal Considerations for the School Nurse

As the nurse well knows, each state has its own nurse practice act governing the scope of practice for the nurse and may limit those nursing tasks that can be delegated to an unlicensed person. When the school nurse has responsibility for several different facilities or is not present at the school site, he or she still maintains responsibility and liability for care delivered. Ensuring that care is appropriately delegated, within the requirements of both the Nurse Practice Act and school administration policy is critical.

Many nurses are unaware of the extent of their liability in these situations, and equally as many struggle with vague language in state laws describing what can be delegated and to whom. Experts recommend that the nurse become as familiar as possible with administration policies that may exist regarding this, but most important know the law. The following four points, delineated in a journal article in *Nursing '89*, can serve as guidelines in helping the nurse determine appropriate delegation.

- **Safety:** Student safety must be the primary concern at all times. If there is concern that the complexity of the task endangers student safety if not handled by an individual with advanced skills, don't delegate.
- **Staffing:** Don't let short staffing predicate who gets a particular assignment or "fills in" in a pinch. Know the skill level and capabilities of all team members to determine who can best do the job. If no one else is capable, don't delegate.
- **Schooling:** Consider all the educational components in a person's background, including inservicing and experience,

before asking them to participate in specific procedures. Make certain you've observed and, if necessary, corrected technique; if not, don't delegate.

- **Supervision:** The keys to safe delegation are adequate supervision and being available should questions or problems arise. If you can't be sure of either, don't delegate.

Adapted with permission from *The Medically Fragile Child In The School Setting: a Resource Guide for the Educational Team*. American Federation of Teacher's Ad Hoc Committee on Health Care Responsibilities in Special Education, 1992.

Section 2

Planning for Safe Delegation

Activity 1

Read and discuss with students the four ways to delegate. Make sure they understand that the initial delegation comes from the school nurse.

These are tips for the school nurse to follow because he or she is ultimately responsible for what happens in the health office. These are good, however, for you as the paraprofessional to be aware of because you may find yourself in a position to delegate some responsibilities on a daily basis.

Your professional judgment of the school nurse is tested routinely in the course of every working day. Yet, when it comes to delegation of duty, the combination of high acuity and low staffing patterns place a strain on even the most experienced professional's judgment. Even so, it's up to the school nurse to remember that the patient, his or her task, responsibility, and license are all "on the line" when they delegate authority, because, while a school nurse may delegate authority, he or she cannot delegate responsibility.

Before a school nurse delegates, he or she should be sure to be familiar with the state's Nurse Practice Act (which is found in Appendix G of this module) and any institutional policies regarding delegation at your place of employment. In some states, the Nurse Practice Act doesn't allow a registered nurse to delegate professional tasks regardless of the education or experience of the licensed practical nurse or nursing assistant to whom the tasks would be delegated. Some institutions limit which professional tasks can be delegated. On the other hand, some institutions attempt to circumvent the nurse and inappropriately assign tasks to institutionally trained personnel.

When delegating, the school nurse needs to ensure that the person to whom he or she is transferring duties not only has the capacity to do the work but is also proficient at it. The nurse, like the paraprofessional, is responsible for the care of patients and has the final word in determining to whom he or she will delegate

nursing tasks. No one else can make that determination.

There are four factors the school nurse should consider when delegating authority:

Evaluate

- The patient's status and needs before determining whether tasks related to care can safely be delegated.
- Staff with whom the school nurse is working. (You should assign duties to licensed personnel before considering others).
- The training and general competence of the person to whom the nurse would delegate.

Educate

- The patient about the fact that some care will be administered by a co-worker in whom the nurse has confidence and whose work the nurse will supervise.
- The person you've chosen about the patient's needs, treatment, and care program, and both explain and demonstrate procedures.
- The nurse's designee about expected outcomes (You should also talk about what circumstances would require your additional help.)

Communicate

- Confidence in the paraprofessional chosen to perform the nursing task(s).
- Expectations for performance and limits on intervention.
- The nurse's receptiveness to discuss any concern, questions or hesitancy about performance of the task.

Supervise

- Directly any co-worker whose skill level the nurse has concerns about, or who is performing the task for the first time (This should be documented.).
- Periodically to reevaluate skills and ensure excellence.
- First and foremost, the school nurse should be available to co-workers and staff.

Adapted with permission from Federation of Nurses and Health Professionals AFT/AFL-CIO: Washington, DC.

Activity 2

Students will read "Delegation and Nursing Practice" in Appendix F. The delegation of responsibilities for a health paraprofessional must come from a licensed school nurse. After the students read this brief description of the school health nurse, refer them to the Nurse Practice Act in Appendix G where you can point out key portions of which health paraprofessionals should be aware. Explain how this would relate to them in a health paraprofessional position. Discuss the implications for nurses in Minnesota.

Activity 3

Students will complete the following chart by either using their own work experience or setting or by interviewing a school health nurse and health paraprofessional team. Make sure the students have first read the previous sections in this chapter before they do this chart. This is a chart that can be used and kept in the health office for reference or could be kept, in a modified version, as an individual record for specific individuals with disabilities requiring regular medical support.

Activity 4

Refer students to Appendix H for a comparison of LSN and SHP, and a delineation of LSN, nurse, and SHP roles.

Roles and Responsibilities

Write in the name and, if appropriate, the date for each responsibility below.

	School Nurse	Health Para
Medication Administration	_____	_____
Record Keeping	_____	_____
Establishing Emergency Procedures	_____	_____
Following Emergency Procedures	_____	_____
CPR, First Aid Training Completed	_____	_____
Safety Issues Addressed	_____	_____

Section 3

Job Description for the Health Paraprofessional

The school supplements the work of the licensed school nurse (LSN) through the employment of the school health paraprofessional (SHP). In this way the school is able to provide more comprehensive health service to a greater number of students.

The school health paraprofessional is a carefully selected individual who has pre-service training that qualifies him or her to function in some of the routine tasks related to the school health service program. The SHP is an unlicensed auxiliary worker with special technical needs.

Job Responsibilities

- The SHP performs services within the school health program under supervision and according to written policies and procedures adopted by the school board and its administration.
- The SHP maintains confidentiality of information learned or received on the job about students and their families.
- The SHP functions with the knowledge and acceptance of the limits of the position.

Relationship to Others

- The SHP receives administrative supervision from the school superintendent, or his designated representative. The SHP receives guidance and direction on health related functions from the LSN.
- The SHP fosters communication between the LSN, the students, the parents, and school personnel for information and request for health service.
- Under the LSN's direction, the SHP assists in recruitment, orientation, and direction of parents/volunteers for school screening programs.
- The SHP's role in meeting the personal care needs of the individual will depend on the degree of the disabling condition, the length of time the person has had the disability, and the stability of the condition.

Content of the Job and Example of Work

- Gives first aid and emergency care as provided for in the school's first aid and emergency care policies.

Discussion 1

Discuss the points of this sample job description with the students. Explain the different components. Ask them to add any other points they feel are important for a school health professional.

Activity 1

Students will read this section and the "Statement on the Nursing Activities of Unlicensed Persons" in Appendix I. Have them relate these rules to the sample job description and discuss it. Then students will complete the activity "Questions to Ask About a Health Paraprofessional Position" by interviewing a school nurse. After conducting the interview and reading the pages above, Students will create their own job description on pages **.

- Participates in screening programs
- Assists in organization of the program
- Performs routine screening procedures
- Assists in training and coordinating use of volunteers according to school policy
- Makes appropriate referrals to the LSN or county public health nurse for follow up of student health problems, and records appropriate information on the public health records.
- Keeps reports for the LSN or county public health nurse for review and possible follow up of student health problems.
- Performs clerical details related to pupil health records, reports, filing, telephoning, ordering and checking supplies and equipment.
- Assists in organizing and participates in:
 - Immunization program
 - Dental program
 - Early childhood screening
- Participates in school injury prevention programs.
- Maintains health room or office.

Qualifications

Academic

- High school diploma
- Clerical skills
- Red Cross Advanced First Aid certificate and CPR
- Demonstrated skills in vision, hearing, and scoliosis screening

Personal

- Ability to maintain positive working relationships with school personnel and the community
- Ability to recognize limitations and to accept and utilize supervision and direction.
- Interest in working with students

Questions to Ask about a Health Paraprofessional Position

Interview a school health nurse and then answer these questions.

- 1 What will my daily duties be?

2 How flexible do you expect me to be with my hours or routine?

3 Who's my immediate supervisor if you aren't in the building?

4 If there's an emergency and you aren't in the building, what procedure should I follow? (Is it posted?)

5 Do individuals with special conditions have individualized health care plans? If so, where are they kept? Do I have access to them?

6 Who are the other members on the health team with whom I will be working?

7 What sort of contact or communication am I expected/allowed to have with parents?

8 Other than health care duties, what other duties are expected of me? (clerical, record keeping, clean up, individual's specific needs, etc.)

9 Do you require that I have CPR and/or First Aid Training? If so, will you pay for the training? How often is the training required?

- 10 Throughout the building, what other duties do you foresee that I will have?

- 11 Other questions or comments:

My Health Paraprofessional Job Description

After interviewing a school health nurse and completing the "Questions to Ask about a Health Paraprofessional Position" and reading the "Sample Job Description" and other readings about expectations of the health paraprofessional, create your own job description below.

- Health Related Responsibilities

- Clerical Responsibilities

- Communication Responsibilities (written and oral)

- Emergency Procedures I must follow

- Other Responsibilities

Summary

For students with special needs, the licensed school nurse (LSN) is often a member of the team for developing, reviewing, and revising the Individual Education Plan (IEP) for students. When the student has special health needs, he or she is an integral part of this team and, with input from the student and family, develops and Individual Health Plan (IHP) and an Emergency Care Plan (ECP). Students who require a paraprofessional to assist them with their health issues, the school health paraprofessional (SHP) works with the LSN. By MN statute, the LSN can delegate some of his or her nursing tasks to the paraprofessional. The nurse is responsible for how the paraprofessional performs these tasks – in essence, he or she works under the nurse's license.

Questions to Ponder

- What relationship do you have with the LSN in your school?
- When the LSN delegates nursing tasks, he or she considers certain criteria. What are they?
- Why is your job description important? What input did you have (or would like to have had) in the development of it?

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Chapter Six

Communication

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- 37 Section 1 Basic Strategies for Clear Communication
- 40 Section 2 Problem-Solving Techniques
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- 53 Questions to Ponder

Introduction

Communication is the exchange of information between two or more people. The biggest issues in communication are that people:

- Do not communicate clearly.
- Do not communicate often enough.
- Forget to communicate with all parties involved.
- Do not really listen to each other.

How you communicate with the staff you work with is essential in being a good team member. Effective communication is crucial to the success of a workable relationship between a paraprofessional and other staff members. When in doubt, communicate.

Section 1

Basic Strategies for Clear Communication

Here are some tips to remember when trying to pay attention to positive communication:

- Active listeners make good communicators. Active listeners have positive attitudes and open minds. By using non-verbal cues, good eye contact, and remembering what was said, they show interest in what the other person is saying.
- The attitudes and feelings of both the supervisor and paraprofessional must be known, respected, and understood. If they aren't shared, the nature of the relationship will not be open or one that grows. Those attitudes cover such arenas as:
 - Individual roles and duties
 - Persons with disabilities
 - Instructional styles
 - Management styles
 - Contributions of others (and each other)
- An understanding of similarities and differences between supervisor and paraprofessional must be recognized and understood. Those similarities and differences may relate to:
 - Values
 - Cultural and religious heritage
 - Levels of education
 - Levels of experience

Discussion 1

Explain to students that a key element to successful working relationships is good communication. Students will read and discuss this section with you and with each other, keeping in mind how important communication is to them on the job. After discussing these basic communication principles, have the students do Activity 1.

Activity 1

Take a clean sheet of paper and draw a line down the middle. Write "my strengths" on the left side and "my weaknesses" on the right. Make a list of your strengths and weaknesses on the job. Include your communication skills as you see them. Share this list with someone on your present job, a family member, or a friend. Be prepared to share this information with the class.

- The health paraprofessional and the health nurse should develop and share a common vocabulary and a system of non-verbal cues. Verbal and non-verbal cues play an important part in communication. Gestures, facial expressions, posture, and eye contact are examples of non-verbal communication. Facial expressions give feedback about whether or not information has been understood, how it's being received, and the listener's attitude about the information. Posture and body movements also communicate attitude. Eye contact and facial expressions give a sense of positive (or negative) relationship between people.
- The supervisor must make sure directions and expectations are clearly understood and that the paraprofessional is able to perform the assigned tasks prior to implementing them.
- The paraprofessional must be willing and assertive enough to ask for clarification or assistance if the assignment is not understood. The paraprofessional needs to explain in an assertive (not aggressive) manner what he or she needs from the supervisor to be successful.
- The supervisor should discuss with the paraprofessional and then decide together what special interests, talents, and training the paraprofessional has that will complement and enhance and improve the delivery of services.
- The paraprofessional and his or her immediate supervisor must work to create a climate of cooperation, trust, respect, and loyalty by meeting regularly to discuss procedures and techniques that will establish and maintain open channels of communication.
- Silence is a form of communication. It's a difficult form of communication to understand because it can mean anger, or grief or depression. It can also mean that the listener understands what is being said. It's important to be assertive in your response when listening so the person who is trying to communicate with you knows your level of understanding and there is agreement. When you remain silent, you block that ability to have cooperative communication.

Communicating with Parents: The Paraprofessional's Role

Sometimes the paraprofessional knows the student better than almost anyone else because of the close relationship they have with individuals on a daily basis. This often creates a strong bond between the paraprofessional and students and their families. In many cases the paraprofessional is also the bus aide and rides to and from school or work with the individual. As a health paraprofessional, you may be directed to make calls home to parents about

health concerns. It may be natural for the parents to establish a relationship with the paraprofessional that is more consistent and regular than with other staff members. Information gathered or discussed in this setting must not be shared beyond the work setting. The paraprofessional must remember a few basic rules:

- Establish some ground rules with your supervisor, if you're in daily contact with parents, so you know clearly what communication is appropriate and what is not. Ask for clear boundaries.
- It may be efficient for you to deliver written contact to parents, but make sure the parents understand that you're only delivering information in behalf of the teacher or supervisor.
- Remember the rules of confidentiality at all times. Don't share information about other students or clients under any circumstances, unless otherwise advised.
- Remember that the teacher or supervisor is the person responsible for setting up instruction and planning for the individual. If the parent has concerns or questions, tell them you will give the information to the proper person, or ask them to make that contact. Never put yourself in a position where you are making decisions with parents that you don't have the authority to make.
- Make sure the student or client knows that you aren't to be placed in the middle of situations between home and school or organization.

The Loss and Grieving Process Related to Disability

Individuals who become disabled usually go through a grieving process involving five stages and is similar to that experienced when someone close has died. The stage a person is in can affect his or her attitude and ability to learn, work, and relate to others. The five stages in this grieving process are described as follows:

- **Denial:** The individual usually tries to ignore the disability and is not very emotional. This is the body's way of anesthetizing itself against the condition.
- **Anger:** The individual expresses rage at what has happened. Hostility is often directed at others. Self-pity often accompanies this stage.
- **Bargaining:** The individual tries to convince him- or herself and others if certain things are done the problem will disappear, and things will be like before (e.g., making promises, trying to "cut a deal"). This is usually the last attempt to ignore the condition before reality sinks in.
- **Depression:** Individuals may become introverted and secluded. At this stage self-pity becomes dominant in the individual. Suicide attempts are sometimes considered.

- **Acceptance:** The individual accepts the loss and its limitations. Plans are made to modify the life-style to achieve a new quality of life.

An individual should be allowed to progress through this process at his or her own rate. They may race through all five stages or skip some, or revert back or linger in one stage. They need help and understanding in order to reach the acceptance level.

- **Other variables** (from class discussion)
-
-
-

As a health paraprofessional, it's important for you to understand these stages because an individual may be referred to you or come to you regularly for medication. You may be one of the few people that sees them alone regularly and you may notice their emotional condition. You may want to talk to the individual based on the stage or process of grieving they may be in. You can be a tremendous support if you know these stages and offer support and understanding to the person. You also may be the person on staff who sees that psychological support may need to be requested for the individual.

All of these are important factors in your understanding the individual and his or her needs. The more you know about the individual's disability and how it has affected him or her, the more sensitive you will be to the need. Take time to ask the individual or read the records about the individual to be able to work most effectively with him or her.

Section 2

Problem-Solving Techniques

It's essential for paraprofessionals and other team members to work through differences in order to succeed in providing the best service to their clients or students.

When working side-by-side, day after day with your supervisor or supervising teacher, you're bound to have differences in the way you each feel situations should be handled. You may have differences revolving around procedure, personal issues, or techniques. The two of you may have different perceptions, learning styles, or clashing emotional needs. The conflict may often come from a source as basic as deciding how to use limited resources.

Conflict isn't necessarily negative. Conflict has some positive functions that are important to remember when working through differences. Some of those positives are:

- Questioning makes people have to clarify their positions.
- Questioning helps others look at different perceptions, concerns, and interests.
- Questioning encourages others to look for new facts.
- Questioning provides a source for developing more specific and long lasting solutions.
- Questioning gives the opportunity to establish mutual trust.
- Questioning results in personal and social change.
- Questioning prevents situation from getting worse.

The following are series of problem solving techniques developed by Anna Lou Pickett in *A Training Program for Paraprofessionals Working with Special Education and Related Services* (developed at the National Resource Center for Paraprofessionals in Special Education and Related Services at City University of New York in 1988). You may find these helpful in improving your ability to work better in a team and with your supervisor.

Step One: Identify and Describe the Problem

A situation must be seen and clearly understood before it can be resolved. It's not always easy to put a problem into words, but if it cannot be stated clearly, it will be impossible to choose a course of action that will lead to a satisfactory solution. Each person must describe the situation in his or her own words and from a personal point of view. This can be done by asking: "What's the problem?", "What's wrong?", "Who's involved?", "Who's affected?", "How are they affected?"

Step Two: Define and Determine the Cause of the Problem

It's essential, next, to determine what caused the problem. Was it caused by outside conditions (such as contractual agreements, budget crunches, etc.)? In this case the team may have little control over the situation, but can work together to decide how to "survive" it together or work to change it. The cause may be a misunderstanding of job roles and responsibilities. The problem may be caused by a difference in values, attitudes, age, work experience, education, cultural heritage, religious beliefs, or other personal traits. Whatever the cause, it must be clearly determined.

Step Three: Decide on a Goal and Identify Alternatives

Now you can develop strategies. Ask yourselves: "What do we want to achieve and how can we go about achieving it?" All those involved in the conflict should brainstorm a list of solutions. More information may be needed in some areas to have a workable list of solutions. Take the time to get all the information needed.

Discussion 1

This material has been added to reinforce the importance of confidentiality, roles, and responsibilities. Remind students of these passages in the training. Encourage discussion on the difficulties that occur when the paraprofessional's put in the middle of situations between setting and home. Brainstorm with students ways to avoid problems. Remind students what is and isn't their responsibility.

Step Four: Select and Implement a Course of Action

All those participating in the brainstorming should decide the solution that will fit the best for all involved. Everyone must agree on the solution, try it out and see if it works, and get back together to revise or change the plan as needed. Before making changes though, all should give the solution enough time to see if it will work since new behaviors and skills don't often change easily.

Step Five: Evaluate the Results

Revising and changing to meet the needs is essential. No solution is ever permanent. The group should regularly evaluate the solution and make adjustments as needed. If the solution isn't working, maybe help from outside sources is needed.

A Problem-Solving Work Session

Use the following steps from this work session adapted from *Building Team Pride* by Margaret Emery at the University of Missouri to help solve the problem and refocus you as a team.

- 1 Maybe the two of you aren't sure where the breakdown in communication took place. There's such tremendous diversity of experience and focus in the nature of your jobs. It's important to remember that you both have the right to be different and to be honored for your differences. Going through the exercise called "Breakdown Checklist" can help pinpoint the problem areas.

You can go through these questions together or individually. Just the act of doing the worksheet can be the spark that helps resolve the situation because as you answer the questions the problem area will become obvious. Then the two of you can talk through the problem and come to a solution.

- 2 If the problem continues or gets worse even after completing the Breakdown Worksheet, the Solution Worksheet will provide a collaborative structure for problem-solving. Notice that four steps exist in this model: *separate*, *focus*, *generate*, and *develop*. Each step requires that you create your response, record your partner's response, and develop a joint response. Therefore, you will need a copy of the worksheet for each of you. This may seem like a very elaborate process to go about problem-solving, but if you practice it as an exercise in class and with your supervisor, it will eventually become an automatic way of dealing with issues and it will become more natural to you to think of these steps in your head.

Teams are marked by mutual ownership. Using consensus during problem-solving discussions is critical to each of you so that you can claim ownership for the outcomes and solutions. Some important guidelines for using a consensus approach are:

- Listen and pay attention to each other.
- Ask open-ended questions using "what" and "how".
- Don't agree too quickly with each other.
- Generate multiple options (challenge the limits!).
- Treat options as alternatives not answers.
- Don't argue blindly for *your* views.
- Treat your differences as strengths.

The two of you will know you have reached a consensus when:

- Both of you agree on a single alternative.
- Each of you can honestly say:
"I believe you understand my point of view."
"I believe I understand your point of view."
"Whether or not I prefer this decision, I support it because it was arrived at fairly and openly and it's the best solution for us at this time."

Twelve Barriers to Communication

Judgement

- **Criticizing:** A judgemental roadblock is criticism. Parents think they need to judge their children or they'll never become hard-working, mannerly adults. Teachers and professionals think they must criticize students in order for them to learn.
- **Name Calling:** "Putting down" or stereotyping the other person: "What a dope!", "Just like a woman!", "Egghead", "You're just another insensitive male."
- **Diagnosing:** Analyzing why people are acting the way they do; playing amateur psychologist. "I can read you like a book." "You're doing that just to irritate me." "You think you're better than I am just because you went to college."
- **Praising Evaluatively:** Making a positive judgement of the other person, or his or her actions or attitudes. "You're always such a good child. I know you'll help me with the lawn tonight."

Sending Solutions

- **Ordering:** Commanding the other person to do what you want to have done. "Do your homework right now." "Why? Because I said so!"
- **Threatening:** Trying to control the other's actions by warning of negative consequences you will instigate. "You'll do it or else..." "Stop that noise right now or I'll keep the whole class after school."
- **Moralizing:** Telling another person what he or she should do.

Activity 1

Students will read "Twelve Barriers to Communication" and discuss these barriers in work, social, and personal settings.

"You shouldn't get a divorce – think of what will happen to the children.", "You ought to tell him you're sorry."

- **Excessive or Inappropriate Questions:** Closed-ended questions are often barriers in a relationship; these can usually be answered in a few words, often with a simple "yes" or "no". "When did it happen?", "Are you sorry you did it?"

Avoiding the Other's Concerns

- **Advising:** Giving the other person a solution to his or her problems. "If I were you, I'd..."
- **Diverting:** Pushing the other's problems aside through distraction. "Just try to think about something more pleasant.", "Think you've got it bad? Look at what happened to me."
- **Logical Argument:** Attempting to convince the other person with an appeal to facts or logic, usually without consideration of the emotional factors involved. "Look – if you hadn't bought that new car, we'd be able to make the down payment on a house."
- **Reassuring:** Trying to stop the other person from feeling the negative emotions she or he is experiencing. "Don't worry: it's always darkest right before the dawn.", "It'll all work out in the long run."

Adapted with permission from training materials developed by the Minnesota Federation of Teachers and the American Federation of Teachers.

Activity 2

Students will use this situation (or another you make up) to work through the Solution Worksheet on the following pages. After this exercise, ask students to share some reactions to the process of the exercises and some outcomes they had with their partners. Relate these outcomes to actual situations.

Problem-Solving Role Play Situation

Role play the situation below with a partner and then consider the questions that follow this scenario.

Scenario: Without the opportunity to talk it through with the school nurse, you made the decision that a student with asthma (which you treated daily) could make the trip on the city bus (unaccompanied) to his job site. Part of that decision came about because you were short-handed, many other paraprofessionals and staff members were out sick, and school nurse and student's parents were unavailable to help make this quick decision. The student reassured you he had his medication needs under control and could take care of them independently. The student made the trip okay, but had expressed some concerns to friends in the hall on his return. The principal overheard these comments and understood the concerns to be much more serious than they were. You, therefore, were held responsible for letting the student go to work unattended. The principal talked to you and the supervising nurse about your "poor decision-making skills".

- What are the issues to resolve in this situation?

- Did the paraprofessional make the right choice of how to handle this situation "in a pinch"?

- After the situation has occurred, how do you think the paraprofessional should talk to the student about what happened?

- To the principal?

- To the supervising nurse?

Activity 3

The focus of the Breakdown Checklist and the Solution Worksheet is to promote a model for working side-by-side attacking problems rather than people. Students will choose a partner and role play the situation on page ** (or make up your own situation that better meets the needs of the group). As homework for next session, Students will use another copy of the worksheets and go through this process with the Breakdown Checklist and the Solution Worksheet with their supervisor at work, a co-worker, or a family member if they aren't in an appropriate work setting. Tell students to be prepared to discuss the outcome.

Breakdown Checklist

Directions: Respond to each question by checking "yes" or a "no". Your responses can be made together or individually. If you choose to work individually, have the teacher use the appropriate checklist column, fold it under, and then have the paraprofessional check the appropriate column. Once you are done with this, discuss the similarities and the differences between answers.

	Para		Teacher	
	Y	N	Y	N
1 Am I sharing information about student performance & growth?	☐	☐	☐	☐
2 Are we conferencing frequently enough?	☐	☐	☐	☐
3 Do we set aside time to applaud each other's successes?	☐	☐	☐	☐
4 Do I recognize my partner's freedom to reject as well as to accept solutions?	☐	☐	☐	☐
5 Do we need to work specifically on any of these areas?				
• Territoriality	☐	☐	☐	☐
• Joint responsibility	☐	☐	☐	☐
• Job descriptions	☐	☐	☐	☐
• Goal setting	☐	☐	☐	☐
• Student evaluations	☐	☐	☐	☐
• Role clarification	☐	☐	☐	☐
6 Are we setting expectations that are too high?	☐	☐	☐	☐
7 Are we setting them too low?	☐	☐	☐	☐
8 Do I focus on present & future issues and not past difficulties?	☐	☐	☐	☐
9 Do I describe to my partner rather than judge?	☐	☐	☐	☐
10 Do I focus on specifics rather than generalities when I talk?	☐	☐	☐	☐

Adapted with permission from *Building Team Pride* by Margaret Emery from the University of Missouri.

Solutions Worksheet: *Differences Lead to Solutions*

1 • Separate People from the Problem

Differences in issue disputes are generally defined by differences in perception between you and your partner.

Goal: *To reduce areas of conflict in perception.*

- Your Response: *I think the problem is...*

- Partner's Response: *My partner thinks the problem is...*

- Joint Response: *Together, we think the problem is...*

2 • Focus on Interests Rather than Positions

For every interest usually exist several possible options that could satisfy it while every personal position generally supports only one interest. Therefore, in order to develop mutual solutions to support several positions, the two of you should focus on clarifying interests.

Goal: *To identify interests behind positions.*

- Your Responses:

The people involved in this problem are...

The problem exists because...

A behavior I display that contributes to the problem is...

A behavior _____ displays that contributes to the problem is...

• Partner's Responses:

The people involved in this problem are...

The problem exists because...

A behavior I display that contributes to the problem is...

A behavior _____ displays that contributes to the problem is...

• Joint Responses:

The people involved in this problem are...

The problem exists because...

A behavior I display that contributes to the problem is...

A behavior _____ displays that contributes to the problem is...

3 • Generate a Variety of Solutions

The two of you aren't trying to search for a single answer, but are trying to broaden options available by generating multiple alternatives.

Goal: *To invent creative options.*

- Your Options: *Three alternatives for dealing with the problem are...*

- Partner's Options: *Three alternatives my partner sees for dealing with the problem are...*

- Joint Options: *Three alternatives we see for dealing with the problem are...*

4 • Develop Situations Based on Criteria

The more the two of you apply standards of fairness, efficiency, and resource availability to bear on problems, the more likely you will be to produce a solution based on consensus.

Goal: *To choose and implement an option based on objective criteria.*

- Your Response: *I would choose option _____ because...*

- Partner's Response: *I would choose option _____ because...*

- Joint Response: We would choose option _____ because...

As the teacher, I will...

As the paraprofessional, I will...

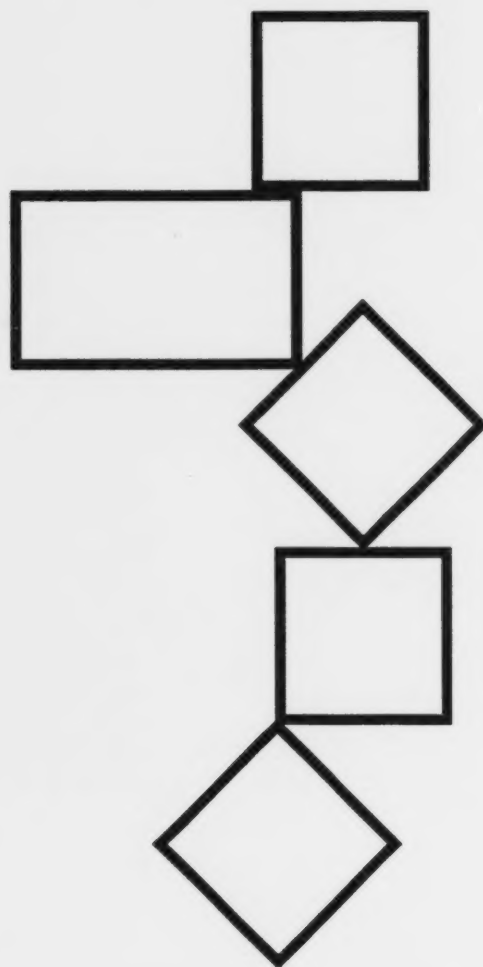
We have the following materials:

We can consult the following resources:

We can ask _____ to assist by...

We can implement this option by _____, and evaluate its effectiveness by observing the following:

One-Way Communication



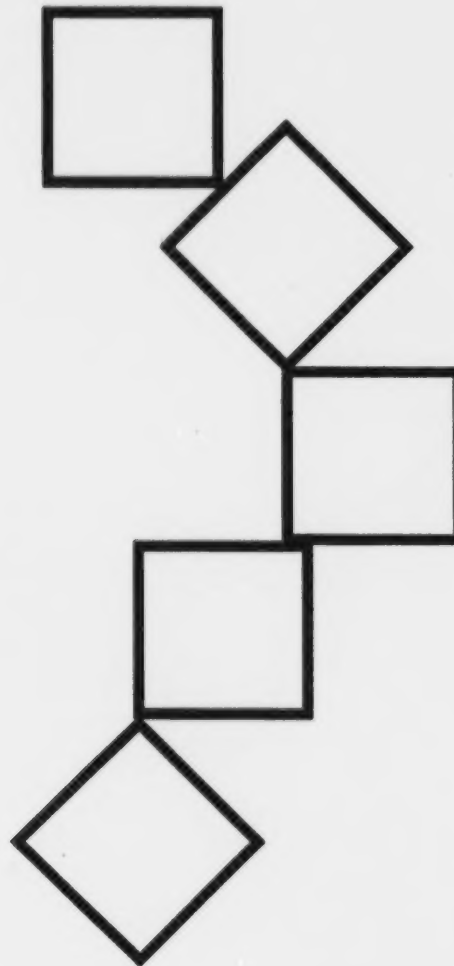
Instructions

- 1 Describe this diagram to the people in the audience.
- 2 Tell them they should draw the diagram following your instructions.
- 3 You may tell them only once and you may not use gestures.
- 4 Tell them the following rules:
 - They can't ask questions
 - They can't talk to one another
 - They can't look at one another's papers.
- 5 Once they've completed this task, have them move on to "Two-Way Communication".

Activity 4

Students will do the activities "One-Way Communication" and "Two-Way Communication". After these exercises discuss what happened. What was the communication like in the first exercise? How did that make the students feel? What was the difference between the feelings students had in the first and second exercises? Ask what they feel caused that difference.

Two-Way Communication



Instructions

- 1 Describe this diagram to the people in the audience.
- 2 Tell them they are to draw the diagram given your instructions.
- 3 You may repeat your directions as often as needed.
- 4 Tell them they may ask questions, get clarification, and use gestures.

"One-Way Communication" and "Two-Way Communication" have been adapted from *A Handbook of Structured Experiences for Human Relations Training, Vol. I, revised*, J.W. Pfeiffer & J.E. Jones, editors, La Jolla, CA: University Associates, Inc., 1974.

Summary

Communication is vital in work relationships, as well as other relationships in life, and it's essential in working with peers, supervisors, students, and students' families. We communicate most obviously by what we say and write, but also through our actions, expressions, and other nonverbal cues. Without quality communication efforts, students would not learn, grow, and develop as they should be able to do.

Questions to Ponder

- Reflect back on a past experience when communication had a positive influence in your life and also on a negative experience when communication was lacking. What have you learned from these experiences?
- How can you use written communication more effectively?
- How does using nonverbal communication influence your message? Give three examples.

7

Chapter Seven

Teamwork

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Individualized Planning
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Teams
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Know to be Effective Team Members
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Introduction

The skills and attitudes a new employee needs on any job vary greatly, but what is important on any job is the ability to work in teams. This is extremely important for paraprofessionals because a paraprofessional will typically be called on to collaborate with many professionals in working with the same student or client. The more effective the team can work together, the better the programming for and with the individual and his or her family.

What is the purpose of a team? For our purposes, a team works together to develop a plan that best meets the needs of those individuals with disabilities with whom it works. The team may work to develop initial planning with an individual and his or her family and/or work together to problem solve situations as they arise.

These goals are important to have an effective team:

- An understanding of each person's role on the team.
- An understanding of the purpose of the team.
- An ability to talk to each other about issues that affect the efficiency of the team.
- A willingness to support each other in the team.
- An understanding of how the team works.
- An ability to effectively work through both interpersonal and task-oriented problems that happen within a team.
- An ability to use conflict in a positive way.
- An understanding that more team collaboration means less competition to provide the best services for the individual.
- An ability to work with other groups to assist the individual.
- A sense of interdependence among team members.

Section 1

An Example of Teamwork: Individualized Planning

A perfect example of teamwork is the development of an individual plan. There are many types of individual plans developed for individuals with disabilities. Some of those are listed below.

Individualized Health Plans

The individualized health plan (IHP) is a written plan used to respond to the needs to the health needs of the student with chronic illnesses or physical disabilities. This plan provides a for-

Discussion 1

Teamwork is as important as communication in determining the success of working relationships. This section will give students some essential ideas about teamwork. Have them read and discuss this section with you.

Activity 1

Students will look at the sample IHP in Appendix J. Walk through the plan with the students so they are familiar with what an IHP contains.

Activity 2

Refer students to the sample IEP from the Minneapolis public schools/department of special education in Appendix K. Walk through the IEP, explaining how it's filled out and by whom. Depending on the group, you may want to assign roles (parent, paraprofessional, nurse, health paraprofessional, psychologist, student, etc.) and role play the IEP process and fill out the IEP form. Emphasize that the IEP process is an example of team participation. Ask the students what the pitfalls of this team process are and where the health paraprofessional fits into IEP planning. Discuss issues related to paraprofessionals being involved in the meetings. Allow students to air their feelings. Ask for some possible solutions to issues related to involvement in meetings. Relate the team process and the IEP format to the additional individual plans listed.

mat for summarizing health information, a problem statement, and goals and objectives. Some of the information may relate to the student's academic needs also if the health condition affects the learning process. (See the example of an IHP in Appendix J.)

Individualized Educational Plan

The Individualized Educational Plan (IEP) is a written plan authorized and developed under PL 94-142 (now PL 101-476, or IDEA). The IEP is a written plan for any student with a disability who qualifies for and receives services in the public school system. Four important requirements of IDEA concern notification, participation in meetings, content of the IEP, and agency responsibility. The IEP describes the student's needs, outlines the instructional program, and defines services needed to meet the student's needs. In order to develop this plan, a multidisciplinary team meets to determine the needs of the student. This team should include the student, parents, school psychologist, the regular teacher, special education teacher, paraprofessional, nurse, any community agency representatives involved with the student, and anyone else involved in planning for the unique needs of students.

The team meets to determine the student's:

- Strengths and weaknesses.
- Learning potential.
- Needs for learning.
- Accommodation or modification needs.
- Learning style.
- Extent he or she will participate in regular education.
- Related service needs.

A plan based on these discussions is written which the student and parents agree to and sign.

Individualized Family Service Plan

The Individualized Family Service Plan (IFSP) is developed for young children with disabilities and their families. The impetus for the development of this plan came out of federal legislation that extended educational provisions under the age of five (PL 99-457). The purpose of the IFSP is to identify and facilitate the use of formal and informal resources that reflect the families' priorities for their children and themselves. The IFSP must include:

- Information on the child's present level of functioning.
- The strengths and needs of the child's family.
- Major goals for the child and family with criteria, procedures and time-line.
- Specific services necessary to meet the needs of the child and family.

- Dates for initiation and duration of services.
- Assignment of a case manager most immediately relevant to the child's needs.
- Steps to support the transition to preschool services

Individual Service Plan

The Individual Service Plan (ISP) is a plan for persons with mental retardation or related conditions who apply for services. The ISP is developed by the case manager with the person with mental retardation or related condition, the person's legal representative, and the person's advocate, if any. The ISP must include:

- Results of the diagnosis.
- Summary of assessment information and recommendations.
- A written summary of needs identified in the diagnosis and assessment.
- Identification of all service needs, including the type, amount and frequency of the services needed, including services to be provided by the case manager.
- Actions that will be taken to develop or obtain the services identified, including those services not currently available.
- Long-range goals and an anticipated date for attainment of goals.
- Annual goals related to attaining the long-range goals.
- Information that providers must submit to the case manager and the frequency with which the information must be provided.
- The signatures of the person and legal representative to document that the ISP has been reviewed and that the person agrees to the goals and service specified.

Individual Community Support Plan

Yet another type of individual plan is called the Individual Community Support Plan (ICSP). This plan is written by a case manager and the person with a serious and persistent mental illness. The ICSP must include:

- Goals for the person.
- Services needed by the individual.
- Goals for each service.
- Amount, scope, frequency, and duration of each service.
- Frequency of face-to-face contact between the person and case manager needed to implement the ICSP.
- Services involving the individual's family or primary caregiver or other interested persons.
- Steps the people and case manager will take to assure the individual's access to services identified in the plan.

Individualized Written Rehabilitation Program

The last individual plan to be cited here as an example of individual plans for persons with disabilities is the Individualized Written Rehabilitation Program (IWRP). Once a person is eligible for vocational rehabilitation services, the counselor assists the individual in identifying vocational goals. Those goals are developed in the IWRP. The vocational rehabilitation counselor will work on this plan with the individual and the case manager and any other agency people. The objectives and services in the plan are designed to overcome the barriers which were identified in the diagnostic study as those keeping the person from employment.

Case Management and the Individual Plan

Each individual plan has a case manager. If the case manager isn't the LSN, the SHP could receive direction from both the case manager and the LSN. Should their directions conflict, the SHP will discuss his or her concerns with the LSN.

Discussion 1

Discuss these points and the importance of each in the role of the paraprofessional in a team work situation.

There might be a lot of discussion about how the paraprofessional doesn't feel a part of a team. Brainstorm with the group for some positive steps they can take to become a more equal member and for ideas of how a paraprofessional can be a member of a team meeting when meetings are held at times they cannot attend. One solution could be for the paraprofessional to develop a written form with his or her supervising nurse to use to relay information about the individual being discussed that clearly addresses the paraprofessional's concerns and experiences about the individual.

The Paraprofessional's Role in the Individual Plan

In each of these individual plans, it's essential that paraprofessionals be involved in the process because they often work most directly with individuals with disabilities. The health paraprofessional should at least be consulted about input in the student planning session. It may be that he or she has little input on many students who don't require special health care, but if the student is a regular in the health office or has any medically fragile conditions, it's imperative that the school nurse and the health paraprofessional be involved in the planning process.

If the paraprofessional is also the bus aide, he or she may also be the one staff member who has regular contact with the parents. Therefore the paraprofessional often knows an individual *and* family's needs intimately. However, in reality the paraprofessional is never involved in the individual plan meetings, which are either scheduled when he or she is not on site (i.e., bus duty), or the paraprofessional is not asked to attend.

It's very important as part of your team development skills that you emphasize the importance of your attendance at these meetings as a paraprofessional. You're a crucial link. At the very least, you need to be given the opportunity to write a report of your work with the students and recommendations. Because paraprofessionals are being given more responsibility, it's essential they also be involved in the planning of the individual plan and given credit as the vital team member.

Results of Workable Teams

- Goals are realistic and possible because everyone contributes in developing them.
- Team is committed and supports each other.
- Priorities are understood and agreed upon.
- Ideas and communication are encouraged.
- Problem solving is done effectively.
- Feedback is honest and "on target".
- Conflict is okay, and is even seen as a normal way to discuss and solve problems.
- Team members get support from each other to be productive team members and productive in their personal goals.
- Team members encourage each other to try new ideas with clients/students and they support each other for those efforts.
- Team members understand the importance of each member in the team and as an individual.

Section 2

Team Members

Role definition is essential to any successful team effort. With an integrated team made up of professionals, paraprofessionals, therapists, nurses, parents, and consumers, it's important to make everyone's role clear. Whether you will be working in a direct service setting or an educational setting, your role on the team needs to be made clear to you. That's the responsibility of your supervising nurse.

As a guideline to typical roles that team members can have, the following is an overview of team roles adapted from a presentation at the 1987 Arc-Minnesota Conference by Linda Kjerland, Judy Neiss, Barb Franke, Chris Verdon, and Ellen Westman.

Roles

Individual with the disability

- Presents personal values and priorities.
- Advocates for personal accommodations or modifications.
- Provides insight into personal goals and future planning.

Parents

- Present family values and priorities for the individual's level of functioning.
-

Discussion 1

This section describes who should be on the team – who the members in the teamwork are. Read and discuss each role with the group and ask students if they have others to add.

Discussion 2

Because this is a guideline of roles in a global sense, emphasize that paraprofessional roles will be discussed in more detail later. Also explain that additions to these team members need to be added for a direct care setting. Ask students what other staff members should be added to this team for direct care, or in settings with which they are familiar.

Activity 1

After they have discussed the "Chain of Command" circle chart in Appendix L, ask students to prepare a chart of the team members and their roles on the team in a site familiar to them for the next session.

- Provide insight into the individual's functioning in various environments.
- Provide a vision of the individual's future.

Regular Education Teachers

- See and include the individual as a member of the class, not a visitor.
- Seek and use others to adapt learning activities to include the individual in meaningful ways.
- Incorporate IEP goals in typical activities and interactions.

Special Education Teachers

- Provide consultation and collaboration.
- Adapt curriculum, materials, and equipment.
- Incorporate IEP goals in typical activities and interactions.

Licensed School Nurse

- Provides health information, daily condition and needs.
- Provides health history, causes, prognosis, etc.
- Provides description and help arrange for special health accommodations needed.
- Provides information for IHP to the team.
- Provide consultation on how to accommodate the individual in the working/classroom setting.

Paraprofessionals

- Facilitate the individual's participation with peers or adults.
- Incorporate IEP goals in typical activities or interactions.
- Assist and perform personal care skills when necessary.

Therapists

- Ensure functional approaches to addressing therapy needs in typical activities and interactions such as self care, getting on the bus, and finding the bathroom.
- Adapt the curriculum, materials, and equipment.
- Incorporate IEP goals in typical activities and interactions.

Administrators

- Draw together regular and special education resources.
- Ensure staff training and team consultative support.
- Assist in problem solving logistics and program issues.

Case Manager

- Bring together the individual with a disability and necessary services and supports.

- Identify the need for planning, seeking out, acquiring, authorizing, and coordinating services.
- Monitor and evaluate the delivery of services.
- Evaluate the delivery of services.
- Protect the rights of the individual.

Section 3

Essential Elements of Effective Teams

Many essential elements make up effective teams and each one works differently in a given team. It's important to understand these elements in your work as a paraprofessional on a team.

Positive Interdependence

This means that each group member sees him- or herself as linked with each other member in a way that one member cannot succeed unless other members succeed. It also means that the work of each member of the team helps you in your efforts and your work helps them in their efforts with the individuals with whom you both work.

Individual Accountability

This means that you and every other member in the team has a responsibility to the group to follow through on assigned tasks with individuals. The team depends on you to follow through. It also means that every member of the team has the responsibility to give extra assistance to each other and offer encouragement to each other when asked for or needed. When everyone on the team is individually accountable in these ways, it's a "safe" environment for everyone and the goal of working for the client's or student's best interests is clear.

Face-to-Face Interaction

This means the amount of actual participation you have in the team. The smaller the team, the more chance you have to be actively involved. The larger the team, the less direct interaction and involvement you have a chance to be involved in. Smaller teams are better. The smaller the team, the more you will feel directly linked to the other members and the easier it will be for you to work directly on the needs of clients or students.

Collaborative Skills

This means cooperation, sharing, and working together for a

Discussion 1

Introduce these elements and discuss them with the class. Discuss the difference between *independence* and *interdependence* and explain the importance of interdependence in team efforts. Explain how important accountability is on their job. Because they have to be so flexible and respond many supervisors it's extremely important for them to devise a way to keep track of who said what about whom. Lead a discussion of what methods can be used to keep one's accountability (e.g., a weekly plan with each supervisor to be evaluated at the end of the week, a calendar for the month with assignments, etc.). Encourage students to develop a small team concept whenever possible so the interaction can be more personal. Explain the complex nature of collaboration and how difficult it can be without good communication. Stress the importance of setting up a communications network with all members or the team and all supervisors. Encourage students to request time from their supervising nurse to evaluate team efforts.

common cause. It doesn't mean personal issues or personalities take importance over the "product" of service delivery. It doesn't mean that people are put together on a team because of their role or position and then not given equal opportunity to contribute. Each team member must feel they have something to share and contribute in providing for the well being of the student or client and they must be allowed to share that information.

Group Processing

This means the team needs to set aside time to talk with each other about how well they are doing working together on their goals for clients or students and their working relationship with each other as team members.

The team needs to develop a good balance between outcome goals (those for the client or student) and process goals (developing an effective team). If the team has some real difficulties with roles (whose job is this?) or positive supportive behaviors toward each other, they may need to call someone from the outside in to help set up some stable boundaries.

Adapted with permission from training materials developed by the Minnesota Federation of Teachers and the American Federation of Teachers.

Section 4

How Teams Really Work

A team has three functions: task functions, maintenance functions, and anti-group functions. These three functions are described below.

Discussion 1

Discuss each of these task functions. Students will give examples of each. Relate team discussions to both education and health care situations. Make sure students understand these are important functions for team members to recognize regardless of their position on the staff.

Task Functions

These functions focus on intelligent problem-solving aspects. These are the actual goals – the reason the team is formed. In the case of a student IEP for example, the team is called together to determine the objectives for the year. Those goals are determined by the group in the following ways:

- **Initiating:** Discussing what could be done or how the challenges of the client or student could be approached. This is when ideas are collected, suggestions are made, procedures are reviewed for possible solutions.
- **Regulating:** Regulating the direction by summarizing what has been done in the past, stating time limitations, restating the goals.
- **Information Seeking:** Asking for additional clarification on suggestions.

- **Information Giving:** Offering facts or generalizations which relate to personal experiences pertinent to the particular situation being discussed.
- **Opinion Giving:** Stating beliefs or opinions about the decision the group should make.
- **Elaborating:** Giving examples or developing further understanding by offering rationale for suggestions made.
- **Coordinating:** Clarifying all the suggestions made for the student or client and trying to decide which suggestions are the most appropriate.
- **Orienting:** Summarizing what has happened, pointing out problems and raising questions about whether more information from outside is needed or if decisions can be made.
- **Evaluating:** Helping the group to evaluate decisions, goals, procedures, and checking to see if the group is in agreement or deciding what further steps need to be taken before a consensus can be reached.

Adapted with permission from training materials developed by the Minnesota Federation of Teachers and the American Federation of Teachers.

Maintenance Functions

These functions focus on the personal relations among members in the group. These functions help a group maintain itself so the focus of the team can be the tasks, the service to clients or students and their families, and not interpersonal conflicts within the group. These ideas can be used by the team leader or any member of the team to work toward building the relationships on the team. This sort of supportive action leads to groups who work much more collaboratively.

- **Supporting:** Creating an emotional climate which holds the group together and makes it easier for each member to want to contribute. One way this is done is in agreeing with the suggestions of others and offering positive feedback when someone makes a suggestion, or adding on to a suggestion with your own additional thoughts.
- **Harmonizing:** Mediating differences between team members or relieving tension with a joke/story about a similar situation.
- **Gate-keeping:** Noticing certain team members who have not spoken and asking them their opinion or asking them to relate something that fits into the conversation. This helps members who may be feeling isolated to come back into the conversation.
- **Encouraging:** Praising and accepting others' ideas. This creates a warmth and a friendly feeling of belonging and helps others become more responsive.

Discussion 2

Ask for specific examples of these types of positive behaviors paraprofessionals have used in team situations. Tell students that these behaviors are also important when working one-to-one with students or clients. Brainstorm with students about how they can encourage others they work with to use these behaviors more frequently.

- **Compromising:** Admitting when you're wrong, or modifying your ideas when you hear other input that makes you realize collaborating ideas creates a stronger decision or choice.

Adapted with permission from training materials developed by the Minnesota Federation of Teachers and the American Federation of Teachers.

Discussion 3

Ask students to give reasons they feel team members or co-workers act in the ways described here; ask for examples. Brainstorm for ways to work with people with these types of behaviors. Ask students to relate times they've acted in any of the "anti-group" ways and why.

Anti-group Functions

These functions focus on members' individual needs and behaviors that can be barriers to completing the group tasks. They don't help the team work as a unit. In these functions, the group goals are forgotten and the individual acts primarily to satisfy personal needs. These are behaviors which, although unavoidable at times, a group works to prevent:

- **Blocking:** Being negative, and unreasonably resistant, trying to bring back issues the group has already rejected.
- **Self-confessing:** Using the group to express personal problems and gain sympathy.
- **Recognition-seeking:** Calling attention to oneself and describing personal achievements and boasting.
- **Dominating:** Attempting to take over by interrupting others, flattery, or asserting superior status, asserting authority or manipulating the group or individuals in the group.
- **Cynical:** bringing up unrelated subjects, being cynical about what team meetings like this accomplish, or displaying a lack of involvement.
- **Special interest pleading:** Stereotyping what is best for others or the group when one is really hiding one's own biases or prejudices in the stereotype used.
- **Aggressing:** Questioning the competence of the people giving their opinions, joking aggressively, showing envy by trying to take credit for others' ideas, expressing disapproval of values, acting on feelings of others.

Adapted with permission from training materials developed by the Minnesota Federation of Teachers and the American Federation of Teachers.

Section 5

What Paraprofessionals Need to Know to be Effective Team Members

In order to be an effective paraprofessional, each person should know and understand these elements of their job.

Job Role

You need to know what your role is and how that role functions within the team. At this point in this training you have done exercises to help you better learn what your role is or should be in a given setting.

Responsibilities

You need to know as much as possible about your responsibilities. In learning what your role is and what a paraprofessional job description is (or should be) in your setting or the setting you chose to explore, you should have a general sense at this point in this training of what the job responsibilities are for a paraprofessional in a general sense.

Goals

Each team's goals are established by its members. First of all, as a paraprofessional, you need to know you're on the team. You deserve to be treated like a team member. You also need to have a clear sense of the goals of the team. Those goals may be set up for one individual. The goals may be basic philosophical goals of the organization or school. You may be on several teams with several different sets of goals. It may seem, at times, like a juggling act to keep the goals separate for each team you participate on, but it's extremely important that you keep the goals separate and clear.

Time

You need the time to participate on teams and to work closely with staff. This is a goal that must constantly be stressed as essential in paraprofessional job roles and responsibilities. To be an effective team, meetings and planning times must be scheduled when members can attend and members must also be given the time to prepare for conferences and staffings. This is all part of being viewed as a valued member.

Communication

You need to know how to communicate well with others. In order to get your views across to others and make your points clear,

Discussion 1

In order to be an effective paraprofessional, one should know and understand these elements. Discuss them as a group.

you need to have good, clear communication skills, as presented in the next section of this training.

Activity 1

Students will complete this activity in small groups, and then come back to the large group and discuss how they resolved the problem concerning Tim.

Activity: How Can You Resolve This Teamwork Dilemma?

Read the following situation, then break up into small groups and discuss how you would handle this situation as a group. Share your ideas with the larger group when you get back together again.

Tim is a paraprofessional in a classroom where there are three other paraprofessionals, four teachers, and twenty-two high school students with multiple disabilities. It seems to the other three paraprofessionals that Tim is out of the room and unavailable every time John needs to be toileted. John is a large student who is difficult to toilet and the staff takes turns. Tim is never available at the right times. When asked about this, Tim says he isn't trying to be unavailable. He always seems to have a legitimate excuse. When the three paraprofessionals went to the lead teacher with this concern, she said the paraprofessionals needed to come up with a system among themselves to work this out.

Assume you're on this team of four. What will you do? Work this through, in discussion, with your group.

Summary

Each individual member of a team contributes to the goal of the team. Alone they will make an impact on the student or family; however, with the whole team working together for the common goal a larger, efficient, more uniform, and consistent impact will be made. Team members who understand each others' roles in the team help the team work cohesively. Other issues to consider are respect of team members, common goals of the team, spirit of collaboration, and team philosophy of interdependence.

Questions to Ponder

- Share an example of team cohesiveness. How did this make the team goals more attainable?
- As a paraprofessional, how do you see your role as a team member?
- Name four ways you can be an effective team member.
- What are three emergency care issues the SHP needs to be aware of?

8

Chapter Eight

Caring for Individuals with Disabilities

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Introduction

This chapter is designed to give the health paraprofessional general background information about the most common types of conditions they may address in the school health office. These conditions represent those which are considered medically fragile or that commonly affect individuals with disabilities. This list was determined by the Minnesota School Health Paraprofessional Advisory Committee in July, 1993.

This chapter presents each condition alphabetically in its own section. Many of these descriptions are taken from fact sheets and publications from local, state, or national organizations that deal with one specific disorder or disease. Each description ends with a summary section called "Why This Information is Important for the Health Paraprofessional".

Our intent is for you to read each section and formulate questions and concerns which you can share in class with your instructor and other class members.

Section 1 *Allergy*

Allergy is an exaggerated response to substances which usually cause no difficulty in most individuals. Our immune system normally protects us from a variety of outside infectious agents, particularly viruses and bacteria. On the other hand, the immune system in some of us actually causes allergic diseases.

Allergy, among the most common diseases experienced by Americans, is believed to affect the lives of as many as forty million children and adults. Taken for granted or often confused with colds or other illnesses, people with allergies can easily dismiss or ignore their causes and, consequently, the various methods that are available to control these very real, disturbing, and often costly diseases.

The most common allergic diseases are:

- **Allergic rhinitis** (or hay fever), appearing clinically as nasal stuffiness, sneezing, nasal itching, clear nasal discharge, and itching of the roof of the mouth and/or ears.
- **Allergic asthma**, with symptoms of wheezing, coughing, and shortness of breath.
- **Allergic conjunctivitis** (or eye allergy), producing redness and itching and chronic mucus-related discharge.
- **Allergic eczema**, an allergic skin rash.
- **Allergic contact dermatitis**, (i.e., poison ivy).

Discussion 1

This chapter is set up to provide basic information to the health paraprofessional on a number of diseases/conditions/disorders. Students will read these facts about each and the comments on how this is important to the paraprofessional and then discuss them in class. You could add greatly to this section by inviting individuals with any of these conditions to discuss them, or families who are involved to speak in class.

Students will read each section to develop an understanding of the disorder/disease, and then discuss key components which are important for them to remember. Encourage students to highlight those key areas or write additional facts in the outside margin.

Some sections end with case studies. Have students form small groups and discuss each case study. Have them then discuss their small group ideas with the whole class and have them use information they have read and discussed to help come up with solutions.

Causes of Allergy

Allergens

The substances that cause allergic disease in susceptible people are known as *allergens*. They enter our bodies in a variety of ways: by inhalation (pollens, dust, mold spores, and cat and dog dander); by ingestion (shrimp, peanuts); by injection (penicillin, insect bites); or by absorption through the skin (poison ivy).

Most allergies of the nose, eyes, and lungs are caused by plant pollens carried by the wind. These pollens are produced at various times of the year when plants discharge literally billions of pollen particles into the air which can be carried significant distances. Unlike the wind-pollinated plants, conspicuous wild flowers or flowers used in most residential gardens are pollinated by insects and are therefore not widely capable of producing allergic disease.

Heredity and Allergy

The capacity to become allergic is an inherited characteristic. Although you may be born with the capability to become allergic, you're not automatically allergic to specific allergens. Several factors must be present for allergic sensitivity to be developed:

- The specific genes acquired from parents.
- The exposure to one or more allergens to which you have a genetically-programmed response.
- The degree and length of exposure.

A baby born with the tendency to become allergic to cow's milk, for example, may show allergic symptoms several months after birth. A genetic capability to become allergic to cat dander may take three to four years of cat exposure before the person shows symptoms.

On the other hand, poison ivy allergy (contact dermatitis) is an allergy in which heredity doesn't play a part. The person with poison ivy allergy first has to be exposed to the oil from the plant. The first exposure may sensitize or cause the person to become allergic and, when subsequent exposure takes place, a contact dermatitis rash appears and can be quite severe. Substances other than plants, such as dyes, metals, and chemicals in deodorants and cosmetics, can also cause a similar dermatitis.

Many people wonder whether or not they will outgrow their allergies. Although allergic asthma and other allergic diseases may spontaneously improve, particularly during childhood and adolescence, it may also worsen or reoccur any time during life. It's no longer thought that people outgrow these diseases. The diseases sometimes do become dormant and free of symptoms. Still, allergic disease can return or even have its initial onset later in life.

Correctly Diagnosing Allergies

A number of diseases can appear to be allergic but upon professional examination prove not to be so. For example, you may have nasal symptoms that are due to chronic and repeated infections and have symptoms similar to allergic rhinitis. Some people with asthma lack allergies to any substance. It's important therefore to show proof of allergy whenever it's suspected because the treatments for allergic and non-allergic disease can be quite different.

Treatment Choices

Self-Improvement

Some people with allergic disease caused by airborne allergens improve by themselves. This can happen for several reasons, such as relocation to an area where the allergens are not found or decreased sensitivity or increased tolerance to allergens due to activation of normal protective immunologic mechanisms.

Interventions

There are several approaches for controlling allergy by reducing or eliminating symptoms:

- Avoid the offending allergen: remain within a well air-conditioned building; learn to recognize and avoid poison ivy and certain foods.
- Take medications: numerous medications, either prescribed or over-the-counter, are available and offer relief for many people.
- Get immunized against allergens to which you are allergic. This form of therapy is usually reserved for more severe cases or for persons in whom other forms of treatment have not been successful.

People with allergies are often susceptible to other substances in the environment. Although substances such as soap powders, cigarette smoke, perfumes, and odors from certain plants surely irritate the respiratory tract of some people, the symptoms they experience are not the direct result of an allergic mechanism. In no way does this minimize the importance of reducing or avoiding these irritants.

Adapted from R.F. Lockey, M.D., et. al. *Asthma and Allergy*. Asthma and Allergy Foundation of America: Washington DC.

Why This Information is Important for the Health Paraprofessional

You may have many occasions to see individuals who have allergies. They may have regular medications you will store and administer. They may have conditions where they react to only certain environments and situations (like bee stings or seasonal allergies). It's important for you to keep a record of individuals who have particular allergies to certain foods, insects, or conditions. It will be your responsibility to alert the school nurse that he or she, the student, and the parents develop an Emergency Care Plan were severe reactions to allergies can be anticipated.

Sometimes these allergic reactions can be so severe that you need to be able to react immediately. Make sure you familiarize yourself with the individuals who have severe allergy reactions. Most individuals you come in contact with will have allergy conditions where you will need to administer medications prescribed by a physician or over-the-counter medications brought from home.

Section 2

Asthma

Asthma is a common respiratory disease that affects an estimated five percent of the American population. Yet, much remains to be learned about asthma, including its cause and prevention. Current medical knowledge and self-education can allow most people with asthma to manage this disease and lead productive, relatively unrestricted lives.

Among the various definitions of asthma, all focus on these principal features: increased responsiveness of the trachea (windpipe) and bronchi (main airway) to various stimuli, appearing as a widespread narrowing of the airways that changes in severity either spontaneously or as a result of treatment.

A number of terms are part of the definition of asthma and key features of this disease. They include the *airways*; *hyperresponsiveness* or *hyperreactiveness*; *obstruction*; and *reversibility*.

It's important that you understand the meaning and significance of these terms, in order to appreciate symptoms, altered lung function, diagnosis, and – most importantly – treatment.

Major Features of Asthma

The Airways

Airways are passageways that carry air into the lungs for the eventual distribution of oxygen to the blood. Airways begin with the trachea (windpipe), which divides into increasingly smaller

tubes as it goes deeper into the lungs. The airways are composed of a number of important parts – mucous membranes, smooth muscle, blood vessels, and nerves – all of which contribute to respiratory symptoms in asthma and the subsequent disease process.

Hyperresponsiveness or Hyperreactiveness

This is the underlying abnormality in asthma, and what separates asthma patients from other individuals. Precisely why or how the bronchial airways in asthma are abnormal is not known. However, as a consequence of this abnormality, the airways in the asthma patient tend to constrict more quickly and easily than in the non-asthmatic person. The hyperreactivity of the asthmatic airways can change and become more sensitive or less reactive when treated. The increase in airway responsiveness sets the stage for patients to have “attacks” of asthma.

Obstruction

The airways narrow during an asthma attack. This is called *airway obstruction*. Obstruction is caused by a number of factors that reduce – or, in extreme conditions, block – air movement as it enters and exits the lungs. Four major elements in airway obstruction are contraction of the bronchial smooth muscle (bronchospasm); mucus formation; inflammation; and edema (swollen lung tissue).

The degree to which these factors contribute to airways obstruction determines the severity of the asthma attack.

Reversibility

The obstructions in the airways during an attack of asthma aren't permanent but may return to normal either spontaneously or, more commonly, as the result of treatment. The bronchial airways typically return to normal soon after treatment, while swelling in the airways takes weeks to disappear. The changes in bronchial tube function aren't permanent nor will they necessarily injure the lung.

Symptoms of Asthma

The usual symptoms of asthma are cough, shortness of breath, and wheezing. In addition, individuals with asthma experience chest tightness, which again can be intermittent, following exposure to a trigger, or continual. The individual can often not tolerate exercise, may experience chronic fatigue from extra effort in breathing, or may even experience weight loss when illness is severe.

These symptoms aren't necessarily confined to asthma. They can be found in association with other lung diseases, such as bronchitis or emphysema. In these and other forms of lung disease, the symptoms are usually present all the time and respond poorly to treatment. There's no one specific symptom or finding that can

be said to conclusively prove the existence of asthma.

Patients with asthma may experience symptoms only occasionally, frequently, or continually. The severity of an individual's asthma can vary greatly, from being a mild nuisance to life-threatening. In addition, symptoms of asthma may be severe in one individual's case while it may not interfere with normal living in another's.

Triggers of Asthma

Symptoms are usually triggered. It's common for a patient to experience symptoms of asthma with exercise, around irritants (including tobacco smoke), with a cold, or during an allergic reaction to allergens such as pollen, dust, animal dander, or certain foods. Symptoms are usually worse at night. Furthermore, it's common for symptoms to become severe enough at night to awaken the patient or even cause the need for prompt emergency care.

Forms of Asthma: Acute vs. Chronic

Acute asthma is usually called an *attack*. The bronchial tubes suddenly narrow and the patient is acutely short of breath and wheezes. Acute asthma can be triggered by allergies, may follow exercise, or occurs during a cold or without any apparent reason. Its suddenness and severity is frightening and creates a medical emergency that requires prompt treatment.

Chronic asthma produces symptoms on a continual basis. In chronic asthma, symptoms, while present, are more difficult to detect because our appreciation of asthma as a chronic, ongoing, persistent illness is a relatively new concept.

Airway Inflammation and Asthma

The major reason for chronic asthma is the existence of ongoing airway inflammation. By inflammation, we are referring to factors that cause airway injury.

Inflammation is more likely to occur and become severe the longer asthma goes untreated. While the signals for the body to produce airway inflammation in asthma aren't fully understood, we do know that there are signals that originate in the lungs, directing circulating white blood cells into the bronchial tubes. Cells already present in the lung also participate in the inflammatory process and cause further tissue injury. When cells either already in the lung or attracted to the lung are activated, they release a variety of chemicals that cause swelling, destruction of airway tissue, and changes from normal lung function. In addition, airway inflammation makes the bronchial tubes more reactive. This means it will take less of a trigger to cause more asthma.

All patients with severe, acute asthma have airway inflammation. Patients with chronic asthma, moreover, have airway inflammation present all the time. It's the development of airway inflammation that leads to chronic asthma.

Allergies and Asthma

Allergies are important in asthma. In allergic people, exposure to allergens stimulates the production of Immunoglobulin E (IgE), the allergy antibody, which signals certain cells to produce and discharge chemical agents that can trigger asthma by contracting bronchial smooth muscle and producing airway inflammation.

It's important to realize that allergies aren't the cause of asthma, but rather are triggers of bronchial obstruction. Allergic reactions in the bronchial tube not only trigger asthma but also cause airway inflammation. Patients with asthma and allergies usually have a family history of allergies and asthma. This suggests that allergies, or the tendency to have allergies, is inherited. The precise role of genetic factors in allergies is not yet fully understood.

Goals of Asthma Therapy

The purposes of asthma therapy include treating the acute episode of asthma and preventing future asthma attacks. This demands combating bronchospasm and airway inflammation.

For asthma patients with allergies, an important goal of therapy is to reduce the likelihood of allergic reactions. This is often accomplished by eliminating the allergen(s) from the patient's environment. Some examples include removing dust-catching carpeting and drapes from bedrooms, and separating the asthmatic person from cats or dogs.

Since it's often impractical or virtually impossible to remove all allergens from the environment, patients must take regular medications to minimize allergic reactions. This prevention concept is very important to the good care of people with asthma. Following this philosophy can go far to allow people with asthma to lead normal, productive, and often unrestricted lives.

From W.W. Busse, M.D., "What is Asthma?", *Advance Plus* (May/June 1990), Asthma and Allergy Foundation of America: Washington, DC.

Why This Information is Important for the Health Paraprofessional

If you're working with individuals who have asthma, they will have medications that you may be asked to store. Individuals may come into your office having asthma problems involved with breathing. Make sure you have an Emergency Care Plan in place, as with the student with allergies. You will need to be able to quickly support their needs and get their medication ready. You should know the individuals who have asthma concerns in your building and keep it on record.

Case Study

Susan is sixteen and a sophomore in high school. This year during volleyball season she had an asthma attack for the first time. She went to the doctor and discovered she has asthma. She was taught how to use an inhaler and now needs to use it during the school day, thus she carries it with her all the time. Because the inhaler is a new concept to her and because she is a little nervous about the whole idea of having asthma, she is having some difficulties using the inhaler properly or at the correct times. One of her teachers notices this and sends her to your health office to discuss this with you. You ask her about her usage and she tells you she takes as many puffs as she thinks she needs, and is often nervous when she uses the inhaler so she breathes very quickly. She seems to be pretty "panicky" about the whole apparatus (the inhaler). What will you tell her? How will you calm her down?

Meet in a small group to discuss this. Then get together in the whole class group and discuss the solutions from your group.

Section 3

Attention Deficit Hyperactive Disorder

The American Psychiatric Association publishes the Diagnostic and Statistical Manual of Mental Disorders (DSM) which is used by medical and associated professionals for diagnosing disorders such as specific leaning disabilities, mental retardation, and autism. Beginning in 1990, the DSM III-R contains a new definition of Attention Deficit Disorder (ADD), now referred to as Attention Deficit Hyperactivity Disorder (ADHD). The essential features of ADHD are developmentally inappropriate degrees of inattention, impulsiveness, and hyperactivity. People with the disorder generally display some disturbance in each of these areas, but to varying degrees.

Manifestations of the disorder usually appear to varying degrees in most situations, including at home, school, work, and in social situations. Some people, however, show signs of the disorder in only one setting, such as at home or at school. Symptoms typically worsen in situations requiring sustained attention, such as listening to a teacher in a classroom, attending meetings, or doing class assignments or chores at home. Signs of the disorder may be minimal or absent when the person is receiving frequent reinforcement or very strict control, is in a novel setting or a one-to-one situation (e.g., being examined in the clinician's office, or interacting with a video game)

In the classroom or workplace, inattention and impulsiveness are evidenced by not sticking with tasks sufficiently to finish them and by having difficulty organizing and completing work correctly. The person often gives the impression that he or she is not listening or has not heard what has been said. Work is often messy, and performed carelessly and impulsively.

Impulsiveness is often demonstrated by blurting out answers to questions before they are completed, making comments out of turn, failing to await one's turn in group tasks, failing to heed directions fully before beginning to respond to assignments, interrupting the teacher during a lesson and interrupting or talking to other children during quiet work periods.

Hyperactivity may be displayed by difficulty remaining seated, excessive jumping about, running in the classroom, fidgeting, manipulating objects and twisting and wiggling in one's seat.

At home, inattention may be displayed in failure to follow through on others' requests and instructions and in frequent shifts from one incomplete activity to another. Problems with impulsiveness are often expressed by interrupting or intruding on other family members and by accident prone behavior, such as grabbing a hot pan from the stove or carelessly knocking over a pitcher. Hyperactivity may be evidenced by an inability to remain seated when expected to do so (this situation varies greatly from home to home) and by excessively noisy activities.

With peers, inattention is evident in failure to follow the rules of structured games to listen to other children. Impulsiveness is frequently demonstrated by failing to await one's turn in games, interrupting, grabbing objects (not with malevolent intent) and engaging in potentially dangerous activities without considering the possible consequences, e.g., riding a skateboard over extremely rough terrain. Hyperactivity may be shown by excessive talking and by an inability to play quietly and to regulate one's activity to conform to the demands of the game (e.g., in playing "Simon Says," the child keeps moving about and talking to peers when he or she is expected to be quiet).

The DSM III-R diagnostic criteria for ADHD is as follows:

- A A disturbance of at least six months during which at least eight of the following are present:
 - 1 Often fidgets with hands or feet or squirms in seat (in adolescents, may be limited to subjective feelings of restlessness).
 - 2 Has difficulty remaining seated while required to do so.
 - 3 Is easily distracted by extraneous stimuli.
 - 4 Has difficulty awaiting turn in games or group situations.
 - 5 Often blurts out answers to questions before they have been completed.
 - 6 Has difficulty following through on instructions from others (not due to opposition behavior or failure of comprehension)

- e.g., fails to finish chores.
- 7 Has difficulty sustaining attention in tasks or play activities.
 - 8 Often shifts from one incomplete activity to another.
 - 9 Has difficulty playing quietly.
 - 10 Often talks excessively.
 - 11 Often interrupts or intrudes on others, e.g., butts into other children's games.
 - 12 Often seems not to listen to what is being said to him or her.
 - 13 Often loses things necessary for tasks or activities at school or home (e.g., toys, pencils, books, assignments).
 - 14 Often engages in physically dangerous activities without considering possible consequences (not for the purpose of thrill seeking), e.g., runs into street without looking.

Please note the above items are listed in descending order of discriminating power based on data from a national field trial of the DSM III-R criteria for disruptive behavior disorders.

Additionally, consider a criteria met only if the behavior is considerably more frequent than that of most people of the same mental age.

B Onset before the age of seven.

C Does not meet the criteria for a Pervasive Developmental Disorder.

Criteria for Severity of Attention Deficit Hyperactivity Disorder

- **Mild:** Few, if any symptoms in excess of those required to make the diagnosis and only minimal or no impairment in school and social functioning.
- **Moderate:** Symptoms of functional impairment intermediate between "mild and severe."
- **Severe:** Many symptoms in excess of those required to make the diagnosis and significant and pervasive impairment in functioning at home and school, and with peers.

Drawn from the *Diagnostic and Statistical Manual of Mental Disorder* (third edition, revised), American Psychiatric Association: Washington, DC. 1987.

Why This Information is Important for the Health Paraprofessional

Many students who are classified ADHD are on medication to help them concentrate in the classroom. You will probably be the person administering the medications during the school day, so you may see the student at least once a day. You will need to understand that some of the behaviors exhibited in your office are a result of the condition

and be prepared to handle them as such. You may also be called on to observe the effectiveness of medication.

Case Study

Fred is eleven years old and in the sixth grade. He has difficulty in academics because he has a specific learning disability affecting his ability to follow directions and sequence. He also is on medication for ADHD. He needs to come to your office every day before lunch to take his medication. This has become a real problem for both you and the classroom teachers because Fred cannot remember to come in on his own. As a result, you or a classroom teacher or paraprofessional are tracking Fred down daily to remind him. This often creates frustration on your part and anger on Fred's part. You meet with the classroom team to come up with a plan to help Fred become more independent and responsible for taking his medication at the correct time. Assume you're with a small group developing a plan for Fred. What will you suggest as the health paraprofessional? Get together in a small group and discuss a plan for Fred. Then discuss your plan with the class.

Section 4

Cerebral Palsy

Cerebral palsy is a condition caused by damage to the brain, usually occurring before, during, or shortly after birth. "Cerebral" refers to the brain and "palsy" to a disorder of movement or posture. It's neither progressive nor communicable. It's also not "curable" in the accepted sense, although education, therapy, and applied technology can help persons with cerebral palsy lead productive lives. It's not a disease and should never be referred to as such. It can range from mild to severe.

Between 500,000–700,000 Americans have some degree of cerebral palsy. About 8,000 babies are born with the disorder each year, and another 500 or so acquire it in the early years of life. The causes of cerebral palsy include illness during pregnancy, premature delivery, or lack of oxygen supply to the baby. It may occur early in life as a result of an accident, lead poisoning, illness, child abuse, or other factors. Chief among the causes is an insufficient amount of oxygen reaching the fetal or newborn brain. The oxygen supply can be interrupted by premature separation of the placenta, an awkward birth position, labor that goes on too long or is too abrupt, or interference with the umbilical cord. Other causes may be associated with premature birth, RH or A-B-O blood type incompatibility between parents, infection of the mother with German measles or other viral diseases in early pregnancy, and

micro organisms that attack the newborn's central nervous system. Lack of good prenatal care may also be a factor.

A less common type is acquired cerebral palsy: head injury is the most frequent cause, usually the result of motor vehicle accidents, falls, or child abuse.

Characteristics

There are three main types of cerebral palsy: spastic, stiff, and difficult movement; involuntary and uncontrolled movement; and ataxia, disturbed sense of balance and depth perception. There may be a combination of these types for any one individual. Other types do occur, although infrequently.

Cerebral palsy is characterized by an inability to fully control motor function. Depending on which part of the brain has been damaged and the degree of involvement of the central nervous system, one or more of the following may occur: spasms; tonal problems; involuntary movement; disturbance in gait and mobility; seizures; abnormal sensation and perception; impairment of sight, hearing or speech; and mental retardation.

Developmental, Educational, and Employment Implications

Early identification of cerebral palsy can lessen developmental problems and lead to appropriate intervention when it helps the most. Early intervention programs are family-centered in which professionals and families work together with the child in specific activities. Educators, physical and occupational therapists, social workers, speech language pathologists, psychologists and physicians can assist families by providing information and education.

Activities for children with cerebral palsy may include:

- Speech and language therapy
- Occupational therapy
- Physical therapy
- Medical intervention
- Family support services
- Early education
- Applied technology

As a child gets older and begins formal schooling, the intensity of services will vary from individual to individual. Persons with cerebral palsy are usually able to attain a substantial degree of independence but, in some cases, may need considerable assistance. Services for the school-age child may include continuing therapy, regular or special education, counseling, technical support, community integration opportunities, recreation and possibly personal attendants. A key factor seems to be a supportive family.

People with extensive involvement can often be highly functional and independent. The HEATH Resource Center, the Clearinghouse for Higher Education and Adult Training for people with Handicaps, states that a significant number of students with cerebral palsy are enrolled in colleges and universities.

Important advances have taken place in the last fifteen years which have had a great effect on the long-term well-being of children born with cerebral palsy. Advanced technology has been applied to the needs of persons with cerebral palsy, including computers and engineering devices. Technological innovations have been developed in the areas of speech and communication, self-care, and adapting living arrangements and work sites. The future may bring even more significant applications.

Another important development has been the increased ability of persons with disabilities, including those with cerebral palsy and other severe disabilities, to live independently in the community. Independent living opportunities include group shared and supervised apartments, or living in the community with appropriate support services. Independent living centers have proven to be important resources for persons with disabilities.

Adapted from a fact sheet by National Information Center for Children and Youth with Disabilities: Washington, DC.

Why This Information is Important for the Health Paraprofessional

Paraprofessionals in the health office may see individuals with cerebral palsy to administer medications, or work with teams on appropriate accommodations in the classroom. You may also be called upon, with the school health nurse, to work with an occupational therapist or adaptive physical education specialist to help plan appropriate programs for the individual. Depending on the extent of involvement, the individuals with cerebral palsy may need no assistance from you for regular support with medication or toilet care.

Case Study

Mike, age ten, considers himself to be like the other children—only with a slight inconvenience: he has cerebral palsy. His condition exhibits itself in a speech impediment, spasms in his back and neck that cause his head to jerk to the back and side, and knocked knees and a swing gait which require him to use crutches to walk.

As a school health paraprofessional, what are some tasks you may assist Mike in completing? Mike participates in adaptive physical education; list possible activities in which he may be involved.

Section 5

Childhood Cancer

Cancer is really a number of diseases caused by the abnormal growth of cells. Normally, cells that make up the body divide and reproduce in an orderly manner, so that we can grow, replace worn-out body tissue, and repair injuries. Sometimes, however, cells get out of control, divide more than they should, and form masses known as *tumors*.

Some tumors may interfere with body functions and require removal, but don't spread to other parts of the body. These are known as *benign* tumors. *Malignant*, or cancerous tumors not only invade or destroy normal body tissue, but, by a process known as *metastasis*, break cells away from the original tumor which then go to other parts of the body where they may form additional malignant tumors.

Children with cancer have a better chance of living a long life than ever before. The survival rates range from more than 55% for children with bone cancer to almost 87% for children with Hodgkin's disease, a cancer of the lymph system.

Cancer is the main cause of death from disease among children from age one to fifteen. Only accidents cause more deaths among children. Each year, cancer will occur in about 7,800 children and cause 1,500 deaths, one third of them from leukemia. In the past forty years, however, the rate of deaths from childhood cancers has dropped by close to sixty percent. These gains are due to research finding new, better, and often less harsh ways to treat cancer. By working as a team, doctors, nurses, other medical care givers, and the child's own parents can keep the child in the best health possible while treating the disease.

Signs and Symptoms

There are several types of cancer that tend to occur in children. The most common are listed first.

Leukemia

Leukemia is a cancer that starts in the body tissues that make the blood, mainly the bone marrow – the soft, spongy center of bones. The most common form of leukemia occurs in children from ages two to six, and mainly in boys.

In a healthy body, worn-out blood cells are always being replaced by newly matured cells. The bone marrow also contains some immature cells. In leukemia, abnormal white blood cells, many of them immature, can crowd out the normal cells in the marrow and then overflow into the bloodstream. Because these white cells aren't mature, they cannot carry out their basic pur-

pose, which is to fight infection. In addition, because so many of these abnormal cells are being produced, the bone marrow cannot make enough normal white cells to fight infection and enough red blood cells to carry oxygen to other parts of the body. This means that a child with leukemia is more likely to get infections and have anemia, a shortage of red blood cells. The child is more likely to have blood loss because there's also a shortage of the platelets that control clotting and prevent hemorrhaging (bleeding that is hard to control).

The early symptoms of leukemia are much like those for colds and flu. The child may look pale, have a fever and loss of energy and appetite.

Neuroblastomas

Neuroblastomas are cancers of the nervous system and the fourth most common form of childhood cancer. The average age children develop neuroblastomas is two. Neuroblastomas are made up of very young and immature nerve cells and can occur anywhere in the body, but usually in the abdomen. The first sign of the disease may be a swelling in that area. In most cases, by the time the cancer is diagnosed it has already spread to the bone, bone marrow, liver, or lymph nodes. For this reason, most children with neuroblastomas seem quite sick at the time of diagnosis. They may have lost weight and be growing more slowly, seem to lack interest, be cranky, and have diarrhea, fever, and pain in the abdomen.

Brain Tumors

Brain tumors, even in their early stages, can cause headaches, blurred or double vision, and dizziness. The child may also have a hard time walking or handling objects. Brain tumors can spread to the spine, but rarely spread beyond the nervous system.

From Facts on Childhood Cancer, American Cancer Society, Inc.

More About Leukemia

Leukemia is a cancer of the blood and develops in the bone marrow, the body tissue that produces blood cells. The bone marrow is a jelly-like substance that fills the inside of the bones.

In speaking about leukemia, "blast" is the short name used for lymphoblasts, the immature white blood cells. There are normal blasts and leukemia blasts. Normally, blasts compose less than five percent of the cells made by the bone marrow and grow to form mature white blood cells with certain typical features visible under the microscope. Leukemia blasts are abnormal because they remain immature and don't function like mature white blood cells. In many cases, they look different from normal blasts when viewed under a microscope.

As the leukemia blast cells accumulate in the bone marrow, they begin to crowd out the normal blood cells that develop there. Eventually, they take up so much room that red blood cells, platelets, and normal white blood cells cannot be produced.

When that happens, the young person develops symptoms indicating that normal blood cells aren't being manufactured in adequate numbers:

- If red blood cells are crowded out by leukemia cells, the blood will look thin, which makes the patient look pale. The young person also may be tired, because the thin blood can not carry enough oxygen to the heart, lungs, and muscles.
- If blood platelets are crowded out in the bone marrow, the young person may have bleeding problems and unusual bruising.
- If the normal, mature kind of white cells known as neutrophils are crowded out by the blasts, there will be no cells to combat bacteria, and infections may occur.

In some cases, leukemia blasts may spill over from the bone marrow into the blood, where they can be seen by microscopic examination. This may cause a rise in the number of white cells in the blood (the white blood cell count). In other cases, blasts appear in the blood, and the white cell count doesn't change much. When leukemia blasts are present in the blood, they may be carried to other places in the body and enter various body organs where they may grow as well as in the bone marrow.

Kinds of Leukemia in Young People

Leukemia is not just one disease. There's actually a type of leukemia for each of the three major kinds of white blood cells – *neutrophils*, *lymphocytes*, and *monocytes*.

Leukemia in any one person can affect only one kind of blood cell. The most common kinds of leukemia are lymphocytic (also called lymphoblastic or lymphoid) and myelogenous (also called granulocytic, myelocytic, myeloblastic, or myeloid). Other types (monocytic, myelomonocytic, progranulocytic, or erythro leukemia) are very rare, but still act much like the more common kinds.

If leukemia affects a young person quickly, it's called "acute" because it comes on suddenly and progresses rapidly without treatment. Almost all childhood leukemias are acute, but the disease is sometimes of the "chronic" type. In chronic leukemia, the bone marrow is able to produce a good number of normal cells as well as leukemic cells so that, compared to acute leukemia, the actual disease course is milder for a period of time. Even without treatment, the disease usually progresses more slowly.

Acute Lymphocytic Leukemia

Acute lymphocytic leukemia (ALL) is commonly known as

childhood leukemia. It's the most common leukemia among the young and is the most commonly occurring cancer in children. As its name suggests, it affects the lymphocytes. Most children are between two and eight years old when diagnosed, but the disease can occur in people in their twenties and thirties as well. For reasons yet to be understood, slightly more boys get ALL than girls, and it occurs more frequently among white children than black children.

Acute Myelogenous Leukemia

Acute myelogenous leukemia (AML) is also called acute granulocytic leukemia. It usually occurs in people over twenty-five, but is sometimes found in teenagers and children. In AML, the leukemia blasts develop from the stem cells that would normally give rise to neutrophils. The characteristics of the blasts in AML are generally similar to those of acute lymphocytic leukemia, but special tests can be done to help determine whether a leukemia is myelogenous or lymphocytic.

Chronic Myelogenous Leukemia

Chronic myelogenous leukemia (CML) is not common in children. CML's distinguishing feature is the presence of very large numbers of immature neutrophil cells, which seem to mature more efficiently than blast cells. The progression of CML varies greatly, sometimes changing to a type of acute myelogenous leukemia.

Diagnosis and Treatment

Diagnosis of leukemia requires blood tests and examination of the cells in the bone marrow, because early symptoms can mimic many other diseases including mononucleosis, anemia arising from other causes, tonsillitis, rheumatic conditions, meningitis, mumps, and other kinds of cancer.

In any acute leukemia, it's necessary to determine which type of white blood cell has become leukemia, because treatment and response to it are different for each kind. The type of leukemia cell involved can usually be determined from its appearance under the microscope, but sometimes special tests of the chromosomes and cell chemistry are needed for complete certainty. In rare instances, the cells are too young to be classified. Such cases are called acute stem cell leukemia or acute undifferentiated leukemia (AUL). Other tests such as X-rays and lumbar puncture may also be undertaken to determine if areas other than the bone marrow are involved.

The primary treatment for leukemia is combination chemotherapy, where two or more anti cancer medications are used to control or eradicate the disease. Radiation, platelet and red cell transfusions, antibiotic therapy, and occasionally surgery (for un-

usual complications) are also a part of many treatment programs. In some forms of leukemia, marrow transplantation is attempted.

Adapted from *Young People with Cancer: A Handbook for Parents*, Office of Cancer Communications, National Cancer Institute and National Candlelighters Foundation, March 1988.

Why This Information is Important for the Health Paraprofessional

As a health paraprofessional, you may notice symptoms that appear to be similar to those listed here and should notify the school health nurse or parents when required to do so. Additionally, if you're working with an individual who has cancer, you need to know the background information about the condition and the individual's personal condition in order to be supportive to the individual and his or her family.

Section 6

Congenital Heart Disease

Congenital heart disease is a condition where a baby is born with a defect in the structure of the heart, surrounding blood vessels, or both. There are more than one hundred fifty different types of congenital heart disease. Some types of heart defects cause obvious problems such as causing the child's skin to look blue. Other heart defects are more difficult to find.

There are a variety of causes for congenital heart disease. The baby's heart develops early in pregnancy and begins to take shape in the third week of development. Many heart defects develop when the heart is being formed, early in pregnancy. Some heart defects are hereditary. Others are caused at birth when expected changes in blood circulation don't occur. Doctors are usually unable to find a direct cause of congenital heart disease.

Symptoms

The symptoms of congenital heart disease vary depending on the size and type of defect. Most children have no symptoms and grow and exercise normally. Some infants and children with heart problems may tire easily, grow at a slower rate, or have a bluish color to their skin, especially when they cry. Some types of congenital heart defects have more severe symptoms than other types. This often depends on the type and size of the defect. Many heart defects cause no apparent symptoms. Children with mild problems often don't need to have surgery to correct the problem.

Health Care with Children from Birth to Age Two

- Infants and toddlers with congenital heart disease sometimes must be hospitalized for surgical repair of the heart or blood vessels. During this time it helps the child adjust if parents are present as much as possible for comfort and support. Hospital staff support parents' decisions about how much time they spend with their child. Many hospitals that care for infant have open visiting hours for family members.
- The child's growth and development should be carefully monitored because some infants tire when feeding and don't eat enough.
- Watch for respiratory infections.
- Assistance can be given in planning to bring the child home from the hospital. If the child needs home care, hospital staff can help make arrangements.
- The child needs the same routine checkups and immunizations that all children need.

Development

- Children develop faster as infants and toddlers than at any other time in life. Most children with congenital heart disease will grow and develop at a normal rate. However, children with some types of heart problems may lack the energy for moving around and seem to have slowed development. The child's development may improve after surgery.
- Some infants get tired quickly and don't drink enough milk to grow. Those babies may need to be fed every two to three hours for a long time if they aren't gaining enough weight.
- Provide a safe environment that allows the child to play with the least restriction. Provide toys and activities that are right for the child's age.
- All children are better able to manage life if they feel good about themselves. It's important to begin building self-esteem early by praising the infant or toddler often.
- After the heart is repaired, expect the same behavior from the child with congenital heart disease as from other children. Set appropriate limits on the toddler's behavior. Children who aren't feeling well may regress in their behavior at times. They may want people to do things for them that they previously did themselves. However, these children have the same needs for love and discipline as other children.

School

- Most children with congenital heart disease will not need special education services. Children with delayed development and special health care needs may be eligible for Early Inter-

vention services which provide services to children birth to age three. In this program, parents are partners in a multidisciplinary team that makes an Individual Family Service Plan (IFSP).

Day Care

- Most children with congenital heart disease can attend regular day care. They usually don't require different care from other children.

Health Care with Children Ages Three to Five

Health Care

- Continue regular health care.
- Children with congenital heart disease need antibiotics prior to having dental care or other surgical procedures. Taking antibiotics before procedures such as cleaning the teeth prevents bacteria from entering the bloodstream and lodging in the heart. If the child doesn't take antibiotics, there's a possibility that heart valves could be damaged by bacteria from the mouth. Health professionals refer to this treatment as *bacterial endocarditis prophylaxis*.

Development

- Provide the child with simple information about congenital heart disease.
- Provide the child with opportunities to do the following:
 - Play with other children of the same age
 - Learn to start and complete activities when playing.
 - Have a balance between structured activities and free time to play.
 - Succeed, so the child gains self-confidence.
- Children who aren't feeling well may regress in their behavior at times. However, these children have the same needs for love and discipline as other children.

School

- Most children with congenital heart disease will not need special education services. Children with delayed development and special health care needs may be eligible for Early Childhood Special Education. In this program, parents are partners in a multidisciplinary team that makes an Individual Educational Plan for the child.
- If the child has any special restrictions on activity, parents should discuss them with the teacher and the school nurse who should relay the information to you.

Health Care with Children Ages Six to Twelve

Health Care

- Continue regular health care.
- Children of this age are generally very active. If the child has special restrictions on activity, parents should ask the child's doctor for guidance in planning an exercise program and relay that information to the teacher(s) and school nurse. Most children don't need to adjust their activity because of a congenital heart condition.

Development

- School-age children understand factual information about congenital heart disease. Give them specific information about their condition in response to their questions. Also, encourage them to talk to their doctor about their condition, and to read about it on their own too.
- Allow the child increasing control over diet and medications. Encourage them to relay to you their needs for medication and diet instead of you asking them.
- Encourage the child to be responsible for remembering when to take medications. Mastering self-care skills will give a child self-confidence and a feeling of accomplishment.

School

- Parents should meet with the child's teachers and the school nurse at the beginning of each year to keep them informed of changes in the child's condition and treatment.
- Children with congenital heart disease usually don't miss more school than their peers. Arrange for homework to be sent home when the child is absent. If the child is absent from school for more than fifteen days, homebound services can be requested. A child is also eligible for homebound services sooner than fifteen days if he or she is absent frequently or the doctor expects the absence to last more than fifteen days.
- Encourage the child to be involved in group activities for children his or her age.

Health Care with Children Ages Thirteen to Seventeen

Health Care

- Continue regular health care.
- Remind the teenager about the benefits of exercise for developing muscles and increasing endurance.

Development

- Some teens with congenital heart disease may enter puberty later than their peers. Reassure the teen that he or she will mature physically, but possibly at a slower rate than other adolescents.
- Independence is necessary for teenagers to develop responsible behavior. Responsible behavior will usually follow independence, if teenagers understand the benefits and consequences of their actions.
- Teens need to understand if congenital heart disease will affect their sexual and reproductive life. They may need encouragement to ask questions. Discuss any specific concerns with the youth and encourage him or her to discuss concern with his or her doctor.
- Smoking is harmful to the health of anyone who smokes, but even more harmful to the teen who has a congenital heart problem.
- Using illicit drugs and alcohol can be especially dangerous to a person with a congenital heart condition. Some drugs can cause an irregular heart beat (*arrhythmia*) or bacteria in the blood (*bacteremia*).
- Peers become increasingly important to teenagers. Teens with high self-esteem can resist peer pressure. They will also be less concerned about being different from their friends.

School

- Encourage the youth to advocate for him- or herself in school. Teens can keep school staff informed of their needs. At some time during adolescence, most teens will resist advocating for themselves. During this time, other family members may need to keep school staff informed of any health care needs.

Health Care with Children Ages Eighteen to Twenty-one

Health Care

- Continue regular health care.
- If the young adult moves away from home, plan ahead for his or her health care. Some young adults find it helpful to find a doctor in the new area before moving. The family doctor may be able to refer the young person to a specialist in the new area.
- When the young adult moves away from home or gets a job, encourage him or her to find out if the current health insurance coverage continues. Some insurance policies will cover young adults only if they attend school as a full-time student. Discuss health insurance needs with the individual, as requested and needed.

Development

- Young adults focus on life goals, education, and careers at this age. Having a congenital heart defect doesn't usually limit career possibilities.

School

- When they move away to school, young adults may want to plan for regular follow-up visits for cardiac problems. Students often continue to see their cardiologist when they visit home.

Adapted from materials provided by the Minnesota Department of Health, Minneapolis, MN.

Why This Information is Important for the Health Paraprofessional

If you're working with an individual with a heart condition, it's important to know what kinds of physical activity restraints the individual must observe as well as the medication, schedule of medication, and diet modification the individual must observe. Talk to the school nurse and the individual about his or her health history, read the records, and ask the parents. Come up with a schedule and a plan for meeting the individual's needs based on this information.

Section 7

Cystic Fibrosis

Cystic fibrosis (CF) is an inherited digestive and pulmonary disorder and is the most common fatal genetic disease in the United States today: CF, a disease which shows no sexual preference and doesn't affect mental ability, affects approximately 30,000 children and young adults. It occurs in approximately one of every 2,500 live births. Approximately 1,300 new cases are diagnosed each year, usually within the first three years of life.

One in twenty Americans – more than twelve million people – is an unknowing, symptomless carrier of the defective gene. Both parents must be carriers of the CF gene for their child to have the disease. Each time two carriers conceive a child, there's a twenty-five percent chance that the child will have CF, a fifty percent chance that the child will be a carrier, and a twenty-five percent chance that the child will be a non-carrier.

The basic defect in CF is created by the faulty transport of sodium chloride (salt) from within the epithelial cells, which line the surfaces of organs such as the lungs and pancreas, to their outer

surfaces. The sweat test is currently the only reliable diagnostic test for cystic fibrosis. This simple, painless test measures salinity of the sweat: a high level indicates that a person has CF.

The pace of cystic fibrosis research accelerated when the CF gene was discovered in 1989. In 1990, scientists successfully made copies of the normal gene and added them to CF cells in the laboratory which corrected the defective cells. The next major step toward gene therapy is now underway: CF researchers, with the continued support of the Cystic Fibrosis Foundation, are refining new gene transfer technology that will lead to a cure.

Symptoms

CF has a variety of symptoms. The most common are salty-tasting skin; persistent coughing, wheezing or pneumonia; excessive appetite but poor weight gain; and bulky foul-smelling stools.

CF disturbs the functions of the exocrine (outward secreting) glands of the body. The mucus produced by the exocrine glands in the lungs is normally thin, slippery and clear. In individuals with CF, this mucus is thick and sticky. It clogs breathing passages and, if not removed, can lead to recurrent lung infections and lung damage. Treatment to help bring up the abnormal mucus often includes bronchial drainage and inhalation of aerosol medications and antibiotics.

Digestion

The thick CF mucus also obstructs parts of the pancreas, preventing enzymes from reaching the intestine to digest food. Without treatment, the body doesn't absorb enough nutrients. Fortunately, the digestive disorders of CF can be helped by ingesting supplementary enzymes and following a special diet low in fat and high in protein, supplemented by extra vitamins, antibiotics, and salt tablets.

Sweat

The sweat of individuals with CF is extremely high in salt. (CF is diagnosed by testing the sweat's salt content.) Individuals with CF may lose a lot of body salt in their sweat, and may actually form salt crystals on their skin.

Treatment

The treatment of cystic fibrosis depends upon the stage of the disease and which organs are involved. One means of treatment, postural drainage (also called chest physical therapy or CPT), requires vigorous clapping on the back and chest to dislodge the thick mucus from the lungs. This can also be done by wearing a special vest to do percussing; the SHP may see these in school. Antibiotics are also used to treat lung infections and are adminis-

tered by pills and/or medicated vapors which are inhaled to help open clogged airways.

Cystic Fibrosis in the Classroom

If an individual in the classroom has cystic fibrosis, you may be puzzled about the disease and apprehensive about how this individual will affect the classroom. Since cystic fibrosis affects each person differently, it's impossible to clearly define the physical health and emotional attitude of the individual with CF. Individuals with CF have the same emotional needs as other children, but group acceptance may be more important to them because this disease makes them feel different. A frequent complaint from young adults with CF is that they're sometimes regarded as "diseased" people rather than as individuals with feelings, hopes, and potential.

The severity of CF varies from person to person, even within the same family. The physical condition of the individual with CF is generally fair to good, allowing him or her to attend school on a full or part time basis. At the other extreme are those individuals with CF whose condition is so severe they can't regularly go to school.

Although there's no cure for the disease, the outlook for individuals with CF has improved dramatically in recent years because of better methods of treatment. Many now live beyond age eighteen. Thus, the average individual with CF can expect to attend high school and to continue his or her education - and life - into young adulthood.

Individuals with CF may cough frequently - and should not be discouraged from doing so. Since CF is not contagious, this coughing is not spreading germs which would cause other children to develop the disease. Some people with CF may feel embarrassed by their coughing: help them feel more comfortable by making it easy for them to slip out of the classroom for a "drink of water". Many children have been taught to expectorate the mucus into a tissue. Paying undue attention to a student's coughing will likely cause other students to do the same. Remember that students often follow the lead of their teacher. Thus, if the teacher accepts his coughing as not that unusual, his or her classmates will think the same.

Physical activity within one's tolerance also helps clear the mucus from the lungs. The planning team, including the nursing staff and parents should consider the individual's limitations when determining his or her physical education grade. Exercise is not only healthy but also provides a psychological boost by promoting feelings of group membership. Include him or her in all games and activities in which he or she is physically able to participate without becoming overly exhausted.

People with CF are particularly susceptible to contagious res-

piratory infections. Thus, in bad weather or during a respiratory epidemic, parents may decide to keep children with CF at home. In the classroom, you can help safeguard students with CF from exposure to other children who have cold symptoms.

From materials from the Cystic Fibrosis Foundation, Bethesda, Maryland.

Why This Information is Important for the Health Paraprofessional

As the school health paraprofessional, you may be called upon to help the individual with cystic fibrosis expectorate the mucus that he or she needs to expel continually. You may need to work with younger individuals to help them learn good hygiene during this process. You may also be called upon to help administer medications throughout the day.

There are striking variations in the severity of the disease. Therefore, treat each individual who has CF as an individual case. The LSN will discuss students' needs with their families and develop plans (IHPs) for you to follow. The individual's physician may have special recommendations. If the individual is unable to attend school regularly, perhaps arrangements can be made for part-time participation or home instruction.

CF is often misdiagnosed as pneumonia, chronic bronchitis, asthma, or malnutrition. If you work with an individual showing CF's special combination of signs (frequent cough, recurrent pneumonia, unusual appetite, frequent bowel movements, small stature and enlarged fingertips), notify the school physician so that the pupil can be tested for CF.

Section 8

Diabetes

Diabetes is a disease that affects the way the body uses food, causing sugar levels in the blood to be too high. About fourteen million Americans have diabetes.

During digestion, the body normally changes sugars, starches, and other foods into a form of sugar called glucose. Then the blood carries this glucose to cells throughout the body where, with the help of insulin (a hormone), glucose is changed into quick energy for immediate use by the cells or is stored for future needs. (Insulin is made in the beta cells of the pancreas, a small organ that lies behind the stomach.) This process is crucial because the body depends on food for every action.

In diabetes, something goes wrong with the normal process of turning food into energy. Food is changed into glucose readily

enough, but there is a problem with insulin. In one type of diabetes, the pancreas can't make insulin. In another type, the body makes some insulin but either makes too little or has trouble using it (or both). When insulin is absent or ineffective, the glucose in the bloodstream cannot be used by the cells to make energy. Instead, glucose collects in the blood, eventually leading to the high sugar levels that are the hallmark of untreated diabetes.

Types of Diabetes

The two main types of diabetes are *insulin-dependent* and *non-insulin-dependent*.

Insulin-dependent (type I) diabetes used to be called *juvenile-onset diabetes* because it occurs most often in children and young adults. But the name was changed after doctors realized it could occur at any age. In this form of diabetes, which affects more than one million people, the pancreas stops making insulin or makes only a tiny amount. Insulin is necessary to life, so the hormone must be injected every day.

Non-insulin-dependent (type II) diabetes used to be called *maturity-onset diabetes* because it occurs most often in adults. In non-insulin-dependent diabetes, which affects almost thirteen million people, the pancreas produces *some* insulin but it's not used effectively. Unfortunately, an estimated six million people have non-insulin-dependent diabetes and don't know it. The people most at risk for this type of diabetes are over forty, overweight, and have a family history of diabetes.

There are other kinds of diabetes, but these are less common.

Gestational diabetes is high blood sugar that first occurs during pregnancy. It usually disappears after the birth of the baby, although nearly fifty percent of these women develop diabetes (usually non-insulin dependent) within five to ten years. *Secondary diabetes* is the type caused by damage to the pancreas from chemicals, certain medicines, or diseases of the pancreas (such as cancer) or other glands.

Impaired glucose tolerance used to be called *latent*, *chemical*, or *borderline diabetes* but is no longer considered to be a form of diabetes. Individuals with this diagnosis have blood sugar cells between "normal" and "diabetic" levels. People with impaired glucose tolerance have an increased risk of developing diabetes.

Symptoms

The following symptoms are typical. However, some people with non-insulin-dependent diabetes have symptoms so mild that they go unnoticed.

Insulin-dependent Diabetes

The symptoms of insulin dependent diabetes usually occur

suddenly. They include:

- Frequent urination
- Excessive thirst
- Extreme hunger
- Dramatic weight loss
- Irritability

Non-insulin-dependent Diabetes

The symptoms of non-insulin-dependent diabetes usually occur less suddenly. They include:

- Any of the insulin dependent symptoms
- Recurring or hard-to heal skin, gum, or bladder infections
- Weakness and fatigue
- Drowsiness
- Nausea and vomiting
- Blurred vision
- Tingling or numbness in hands or feet
- Itching

Prevention and Treatment

The causes of diabetes are still a mystery, but researchers believe that the tendency for diabetes is present at birth. In insulin-dependent diabetes, any of several different viral infections and a process called *autoimmunity* are believed to trigger diabetes. In the autoimmune process the body's defense system attacks its own cells, the insulin-producing beta cells in the pancreas. Note that although viruses may help to cause some cases of insulin-dependent diabetes, diabetes is not contagious. In people prone to non-insulin-dependent diabetes, being overweight can cause diabetes, because excess fat prevents insulin from working properly.

So far, insulin-dependent diabetes can't be prevented, although researchers are working on many promising approaches. Insulin dependent diabetes is treated with daily insulin injections, regular exercise, and a balanced meal plan that limits sugar. Such a meal plan will be tailored to the individual's needs and is likely to include three meals and two or three snacks a day at set times each day to properly balance insulin, which is also given at fixed times. (Insulin lowers blood sugar, and food raises it: to control diabetes, you need to balance these effects.)

Non-insulin-dependent diabetes can often be prevented by maintaining normal body weight and keeping physically fit throughout life. A major aim of treatment is to control blood-sugar levels, which means keeping them in the normal range. Research suggests that tight control can help prevent or delay long-

term diabetic complications. Non-insulin-dependent diabetes is treated with an individualized diet plan that restricts calories. If you're overweight, you need to slim down. Treatment also includes restricting sugar and following an exercise plan. These steps should improve your body's ability to use its insulin. If diet and exercise alone don't control blood sugar, prescribed pills or insulin may be needed.

Testing

Two types of tests are used to monitor blood-sugar levels: blood tests and urine tests. Blood tests, done by pricking the finger for a drop of blood, are recommended by most doctors because they give the exact amount of blood sugar at any given moment. Urine test readings are a crude indication of blood sugar, and are much less direct and much less precise. People with insulin-dependent diabetes are often advised to test sugar levels two to four times a day, before and after meals. People with non-insulin-dependent diabetes may be able to test less often. Tests that measure ketones in the urine are also important. Ketones are acids that collect in the blood and urine when the body uses fat (instead of glucose) for energy. Ketones in the urine are a sign that diabetes is poorly controlled and that prompt attention is needed. Always test for ketones when you're ill or under great stress, the times when diabetes is likely to go out of control. Be sure to record the results of all your self-tests. These records are useful guides for adjusting food, medicine, or exercise when blood sugar is too high or low. Another important test, done by a doctor every three to six months, is a "glycohemoglobin" test. This measures the average blood-sugar level over the past thirty to sixty days.

Problems to Handle Promptly

Hypoglycemia

Hypoglycemia, low blood sugar, is sometimes called an *insulin reaction* or *insulin shock*. It can occur suddenly in people using insulin if too little food is eaten, if a meal is delayed, or if extra exercise is done. It's less common in people whose diabetes is treated with pills but can occur. Low blood sugar must be treated quickly, with sugar or sugary foods because, when untreated, hypoglycemia can lead to unconsciousness. The typical symptoms include feeling cold, clammy, nervous, shaky, weak, or very hungry. Some people become pale, get headaches, or act strangely. If a person becomes unconscious, glucagon, a hormone (available by prescription) that raises blood sugar, must be injected.

Hyperglycemia

Hyperglycemia, or high blood sugar, occurs when too much food is eaten or not enough insulin is taken. Illness and emotional

stress can also cause high blood sugar. The warning signs are large amounts of sugar in the urine and blood. You may also urinate often, be very thirsty, and feel nauseated. Treat high blood sugar with the help of your doctor.

Ketoacidosis

Ketoacidosis, or diabetic coma, may accompany high blood sugar. It develops when insulin and blood sugar are so out of balance that ketones accumulate in the blood. High levels of ketones are poisonous. Fortunately, ketoacidosis, which develops over several hours or days, can usually be avoided if diabetes is brought under control at the first signs of high blood sugar or ketones in the urine. (Call the doctor for instructions.) In addition to high blood and urine sugar levels and high ketone levels, the symptoms include dry mouth, great thirst, loss of appetite, excessive urination, dry and flushed skin, labored breathing, fruity smelling breath, and possible vomiting, abdominal pain, and unconsciousness. Ketoacidosis is most likely to occur in people with insulin-dependent diabetes. Anyone with diabetes should wear a medical ID necklace or bracelet stating the type of treatment they use in case of emergencies.

Long-Term Health Problems

Diabetic complications are usually caused by changes in the blood vessels and nerves. Unfortunately, they can include eye and kidney disease, heart attack, numbness or pain in the legs, foot infections leading to gangrene, and stroke. Fortunately, however, treatments continue to improve. Also, many researchers now believe that keeping blood-sugar levels tightly controlled from the moment of diagnosis can help to prevent complications. Excellent control is especially important for diabetic women who want to become pregnant, because tight control from before conception helps to prevent birth defects.

Adapted from information from the American Diabetes Association, Diabetes Information Service Center, Alexandria, VA.

Why This Information is Important for the Health Paraprofessional

The individual with diabetes will be seen in the health office for several reasons. The most common is blood sugar testing. Most individuals learn how to do their own blood sugar testing, if they are able, and the health paraprofessional only is there to take out the medication and supervise. Individuals may come in if they need to check their blood sugar and eat quick snack. Most individuals who are able to learn to monitor their own needs and are efficient at asking for what they need to regulate themselves.

Case Study

Joe was diagnosed with diabetes at age two. At fifteen, he's a sophomore this year. His daily routine at school is to snack mid-morning and do a glucometer test. He does the same just prior to physical education class to insure that his blood sugar is stable. Joe's blood sugar tends to fluctuate, however, so that on any given day, he may need to come to the health office. He usually comes with a "buddy" from class because it's better for him to have someone accompany him due to symptoms of "low" blood sugar. For Joe, these symptoms are shakiness, headache, and blurred vision. A blood sugar check confirms his symptoms. He then immediately eats a fast-acting sugar, such as gluco-tablets, followed by a snack such as cheese and crackers. He then he re-checks his blood sugar in fifteen to twenty minutes. If it's returning to his normal range, he feels better, but needs to eat something substantial, such as milk and a sandwich, or lunch if it's lunchtime.

This is Joe's daily routine. He needs to self-manage and "read" his body experience at all times in order to manage his diabetes. To assist him, the school nurse developed an Emergency Care Plan to inform school staff about his diabetes, his symptoms (when his blood sugar is "low") and then a plan of action.

It's important to remember that diabetes is a lifetime condition and that students need support, understanding, and encouragement.

Pretend you're the health paraprofessional at Joe's high school. You're particularly sensitive and supportive: Joe has responded to your attitude with a very positive outlook himself. Because you have such a good relationship with Joe, the school health nurse has asked you to develop some ideas for a new Emergency Care Plan for Joe for this school year. In the space provided below, write down the main points that will have to be in his plan, baser on his needs. Make a tentative schedule for Joe. Be prepared to explain why you made the plan the way you have and be ready to discuss it with the class.

Section 9

Eating Disorders

Approximately six in 1,000 young women suffer from anorexia nervosa. Persons with anorexia nervosa may be young or old, black or white, rich or poor, female or male.

Bulimia nervosa is more common than anorexia nervosa, and it's believed that at any point in time five to ten percent of females between twelve and twenty-four years of age display significant bulimic behaviors. Although bulimia tends to develop in late ado-

lescence and early adulthood, it can occur at any age. It's important to note that at least forty percent of people with anorexia nervosa also suffer simultaneously from bulimia.

Most individuals with bulimia are women, but this eating disorder does occur in men: ten to twenty percent of adolescents with eating disorders are male.

Individuals who are at risk tend to display some or all of the following traits: one's self-esteem based on weight; constant thoughts about "feeling fat"; repeated attempts to diet; self-consciousness or embarrassment about eating; compulsive exercising; isolation; perfectionism; eating for emotional comfort; over-achieving; limited emotional expression; and ritualistic behavior around food. There are also numerous physical problems individuals with eating disorders may display:

- Cessation of menstruation; loss of sexual interest
- Chronic kidney problems
- Irregular heart rhythms
- Irritation and tears in the esophagus
- Parotid gland swelling (under jaw-line)
- Erosion of tooth enamel and increased cavities
- Electrolyte imbalance
- Growth of lanugo (fine hair on body surface)
- Muscle cramps
- Light-headedness and dizziness or fainting
- Unusual sensitivity to cold
- Dry skin and thinning scalp hair
- Stomach and intestinal problems
- Unexplained swelling (edema)
- Chronic constipation and other colon problems.

There are numerous similarities between anorexia and bulimia, including a preoccupation with dieting, food, weight, and body size; discomfort when eating with others; severe changes in habits, mood, and personality; hyperactivity; difficulty with concentration and sleep; complaints of fatigue, headaches, edema, and paresthesia; approval-seeking behaviors; and problems with interpersonal relationships.

Despite these similarities, there are equally significant differences between the two disorders. Individuals with anorexia tend to be introverted and preoccupied with losing more and more weight; deny any abnormal eating behavior; turn away food to cope; and have a distorted body image. Individuals with bulimia are frequently extroverted and preoccupied with attaining an ideal, unrealistic weight; recognize abnormal eating patterns; turn to food to cope; and experience dissatisfaction with body weight and shape.

Anorexia Nervosa

Anorexia nervosa is an emotional disorder characterized by severe weight loss (or failure to gain weight in young people). Individuals with anorexia nervosa have an unyielding determination to become thin, and an intense, irrational fear of becoming fat, both of which often increase as weight is lost. In lay terms, anorexia nervosa involves "dieting gone wild".

Persons with anorexia nervosa vigorously refuse to maintain a healthy weight. Weight is lost through a variety of methods, including severe caloric restrictions, fasting, relentless exercising, use of over-the-counter diet aids, diuretic and laxative use, and, in some cases, self-induced vomiting. Most individuals suffering from anorexia nervosa strongly deny the disorder in part because they often "feel fat" even when they are very thin. Moreover, they experience a sense of control by restricting food intake and often turn away from food in an attempt to cope with life's stresses.

Symptoms of Anorexia Nervosa

- Abnormal weight loss of ten percent or more with no known medical illness accounting for the loss.
- Restriction (reduction) of food intake.
- Denial of hunger and/or the problem.
- Decrease in the consumption of foods containing animal fats.
- Intense fear of weight gain and/or a "grim determination" to become thinner and thinner.
- Abnormal reproductive functioning; i.e., amenorrhea in women, low testosterone levels in males.
- Prolonged exercising despite fatigue and weakness.
- Peculiar patterns of handling food.
- Distorted perception of weight, body-size and/or shape.
- Inability to control weight-loss and amount of exercise.
- Social withdrawal.
- Unusual sensitivity of the cold.
- Perfectionism paired with a profound sense of ineffectiveness.
- Weight loss through use of vomiting, diuretics, and/or laxatives.
- Lanugo (fine hair on body surface), symptoms of starvation.

Bulimia Nervosa

Bulimia nervosa is an emotional disorder which consists of episodes of binge eating followed by some form of purging and/or severe dietary restraint. A "binge" is the secretive consumption of large amounts of food in a short period of time. Most bulimics

follow the binge by self-induced vomiting, but "purging" may take the form of laxative or diuretic abuse, fasting, abuse of diet pills, or strenuous exercise. This binge-purge cycle is normally accompanied by self-depreciating thoughts, depressed mood, and an awareness that the eating behavior is abnormal and out of control.

In most cases the binge-purge cycle is an outlet for feelings of frustration, disappointment, anger, loneliness, or boredom. In this regard bulimia nervosa may be accompanied by other impulsive behaviors such as shoplifting, self-injury, and/or the abuse of alcohol and other drugs. It's also important to note that a person can be anorexic and bulimic at the same time.

Symptoms of Bulimia Nervosa

- Fear of weight gain.
- Distinct and often uncontrollable, secretive episodes of binge eating followed by attempts to purge the food through self-induced vomiting.
- Unhealthy dieting and/or use of laxatives, diuretics, or diet aids.
- Depression and recurrent mood swings.
- Prolonged exercise for the purpose of weight control.
- Inability to discontinue the binge-purge cycle.
- Problems with the throat, esophagus, stomach, and colon.
- Edema and swelling of the parotid glands.
- Dental problems.
- Emotional instability and impulsivity.
- Dissatisfaction with body shape and preoccupation with becoming thin.
- Frequent weight fluctuations.

Supporting Someone with an Eating Disorder

Living and working with a person who has an eating disorder is a very difficult and trying experience. If you're close to someone you suspect has an eating disorder, you may want to consider some of these suggestions which may minimize the discomfort and help resolve the problem.

Don't make comments about the individual's food intake, eating habits, or weight. Make sure she or he is under a physician's care, and contact the parent and/or physician with any concerns you have. Parents aren't responsible but may feel very guilty. The illness is very complex, and no one person or event caused it. Once the individual's physical condition has been checked out, encourage that he or she get psychotherapy: then getting well becomes their responsibility. Step back and allow them to be responsible for their own recovery. Neither you nor the family can "fix" or make

them well.

Recognize that the individual's behavior is likely to cause parents to feel helpless and angry. Most families of children with eating disorders find that coping with the child's illness is anger-provoking and frightening. Recognize and accept these feelings. However, rather than expressing them to the individual, it's suggested that you encourage the family and the individual to seek counseling or a support group.

In conflicts about decisions, parents should not retreat from their own positions out of fear that their child will become increasingly ill. As an outside support, you should maintain a supportively confident posture in dealing with the child. This is not to suggest that harshness, rigidity, or anger need to be used, but rather that you be consistent and caring.

Support the individual by expressing honest interest toward her or him through verbal and physical expression. Do not put them down by comparing them to more "successful" students or friends. Their self-esteem is a reflection of others esteem for them. Affirm them for who they are, rather than for their accomplishments, performance, or looks. They are constantly looking for praise or criticism in these areas – don't get hooked into giving it.

Do everything you can to encourage the individual's initiative, independence, and autonomy. Trust them to find their own values, ideals, and standards as they approach adulthood. They have a lot of fears about becoming independent and parents and other adults are often reluctant to encourage this process.

Tips for Helping a Person Who May Have an Eating Disorder

- Encourage progress, not perfection.
- Encourage responsibility and accountability for actions.
- Avoid driving individuals to excel beyond their capabilities.
- Medically necessary weight changes should be supervised under a physician's care.
- Exert caution in commenting on appearance.
- Communicate love and care regardless of weight.
- Collect information about anorexia and bulimia and about local sources for treatment or support. Keep a file of this information in the health office. A good place to begin is your local mental health association or health professional.
- In a caring and non-judgmental way, tell the person what you have observed in the way of anorexic or bulimic behavior. Suggest they seek physical and psychological assessment by a qualified professional. Give the individual the phone number and name of a treatment source.
- If the person is a minor, discuss your observation with LSN,

teachers, or guidance counselors (check your community's law and regulations). As a paraprofessional, you should first discuss your concerns with your supervising health nurse. Do not promise to keep the eating disorder a "secret."

- If the individual and/or the parents deny there is a problem, consult with supervisors who will discuss treatment resources, children's services, or local health services for what to do next. Be patient, and let the individual know you are both concerned and available for further consultation.
- When a person begins treatment, be natural and caring with them, but don't discuss eating, weight, or appearance. Do not insist that the person eat or change attitudes. Become involved in activities and discussions with them that don't center around food and weight issues.

Information in this section was adapted from fact sheets developed by Fairview Riverside Mental Health Services, Minneapolis, MN.

Why This Information is Important for the Health Paraprofessional

A student with an eating disorder will often come into the health office complaining of related ailments. At first glance, the ailments may not seem to be related to an eating disorder, but the astute health paraprofessional who can piece together a series of complaints may be able to determine that the real problem is an eating disorder. Another important reason for the health paraprofessional to be informed about eating disorders is to serve as a resource to other staff who may have concerns about students. It would be valuable to have a file of information similar to the information above to share with concerned parents or staff. Because eating disorders are so prevalent, you will want to know the basic characteristics.

Case Study

A fourteen year old girl is referred to the health office in her middle school because the teacher is concerned about her. Alice is in the teacher's English class just after lunch each day. To the teacher, she seems preoccupied with dieting but at the same time is very thin. She complains everyday of headaches and fatigue. She is a very good student and is a perfectionist about her work. She becomes very upset if she makes any mistakes. She's on the track team and is a long distance runner. When Alice comes in, you recognize her as a student you have seen in the office for a variety of small ailments that never seem to "amount to anything". On receiving the teacher's referral, you begin to piece some facts together and think maybe Alice has an eating disorder. How will you handle this with Alice? Who should you consult with? What immediate action should you take? What long range plans should you

make or suggest? Get together in a small group and discuss some ideas. Has anyone in the group had such an experience? Come back to the larger class group with your suggestions as a team.

Section 10

Emotional/Behavioral Disorders

Individuals who behave in ways that significantly interfere with their learning and with developing positive relationships with others are often found to have a disability called an emotional/behavioral disorder, or E/BD. These individuals usually have low self-esteem and poor social skills – that is, they haven't learned appropriate behaviors to get along with others. They may have some learning disabilities but are often very bright and capable.

There are several types of emotional/behavioral disorders:

- **Aggression:** Physical or verbal behaviors meant to hurt others.
- **Disruptiveness:** Behaviors that disrupt the classroom, i.e. getting out of seat, making noises, throwing objects, talking out, and interrupting.
- **Noncompliance:** Uncooperativeness with requests and suggestions and unwillingness to follow directions. Individuals with attention deficit hyperactivity disorder (ADHD) often demonstrate some of these behaviors.
- **Temper Tantrums:** Characterized by acting-out behaviors including crying, stamping, throwing self, screaming, kicking, clinging, jumping up and down, shouting, pounding, etc. Tantrums are most often found with toddlers and young children.
- **Stereotypic Behavior:** Repeated actions or responses that may be self-injurious or self-stimulatory. These behaviors are most commonly observed in children who are autistic or severely mentally disabled.

Childhood depression, anxiety disorders, fears and phobias, obsessive compulsive disorders, and schizophrenia are also included with E/BD.

Causes of E/BD

Almost anything can cause E/BD behaviors. The four main factors that interact to influence behavior are biology, family, school, and culture. E/BD type behaviors may be triggered by environmental stresses and/or incidents that are seen as threatening by the individual. For example, an individual may feel frustrated with an assign-

ment or task, but instead of asking for help he or she may act-out or shut down. These individuals often try to get attention through negative behaviors such as acting like the class clown, "smarting off", or simply refusing to do work. These are behaviors they have learned: don't expect them to "know better". They need to be taught the appropriate behaviors. It's important to keep in mind that the individual may have feelings of fear, discomfort, anger, humiliation, self-hatred, and despair. They need support and encouragement.

Tips for Helping an Individual with E/BD

- Be proactive!
- Give the individual choices.
- Listen; be patient.
- Give warnings about events (so he or she will know what to expect).
- "Catch individuals being good" and/or following rules and praise them!
- Rearrange the environment to prevent problems.
- Find strengths and emphasize them; build self-esteem!
- Help match individuals up with a potential friend.
- Let the individuals be useful and helpful to you.
- Use a problem-solving method. (See the section "Behavior Assistance/Crisis Intervention Team" below.)

There are also a variety of things to stay away from when working with an individual with E/BD:

- Reacting: you need to stay calm and in control.
- Using a loud voice: this will only increase the problem. Use a soft but firm tone and respectful language.
- Saying things like, "No, you can't."
- Getting into power struggles and arguing with the individual. (This is what the individual may be used to and arguing is a lose-lose situation).
- Physical struggles: unless the individual is hurting themselves or others, avoid touching or holding. It's important to give the individual some space and time to regain self-control. If a restraint is necessary, a gentle but firm basket hold may be used.
- Finally, you should keep in mind that these individuals have a hidden but very real disability. They should be treated with respect, understanding, and great care. They aren't to blame for their E/BD behavior. Know that, anything you do to be proactive will make a tremendous difference in these individuals' lives!

Adapted by Karen Kozen from T.J. Zirpoli & K.J. Melloy. *Behavior Management: Applications for Teachers and Parents*. Columbus, Ohio: Merrill/Macmillan, 1993.

Behavior Assistance/Crisis Intervention Team

These are steps for developing a problem solving plan:

- 1 De-escalate the individual. Be calm and personalize situation:
"I care about you (individual's name) as a person and a learner, I'm here to help you solve the problem."
- 2 Identify the behavior: "What did you do?"
- 3 Make a value judgment: "Is it helping you?" "Is it helping others?" "Is it against a rule?"
- 4 Work out a plan: "What can you do differently?"
 - Alternate behavior
 - Discuss appropriate behavior choices
 - Give rational for appropriate behavior
 - Practice appropriate behavior (i.e., give scenario and role play)
- 5 Make a commitment: "Will you do this?" Sign a contract.
- 6 Explain both rewards and consequences for future behavior choices.
- 7 Write apologies, enabling the student to return to classroom with a "clean slate".
- 8 Praise the student for cooperation; plan a time for checking in as follow-up for the plan.

Adapted from William Glasser's "seven steps to effective discipline" model: "Teaching Interaction Steps for Inappropriate Behavior and Crisis Intervention" by Kris Melloy, Ph.D.: from materials developed by Karen Kozen; and from T.J. Zirpoli & K.J. Melloy. *Behavior Management: Applications for Teachers and Parents*. Columbus, Ohio: Merrill/Macmillan, 1993.

Why This Information is Important for the Health Paraprofessional

Paraprofessionals working in the health office may see individuals with emotional or behavioral disorders. They may enter with a condition that is related to their behavior for which they need medication, such as ADD or ADHD, or they may need assistance as a result of an injury related to an outburst. For whatever reason you may have encounters with individuals with E/BD, you will need to know how to appropriately react and treat these individuals. This section give you background and a problem solving technique to help work with individuals who may have E/BD.

Case Study

Jonathan, who is eight years old, frequently comes to see the SHP in the health office with various "emergency" situations. Today he came into the office with another third grader after activity period. The other child says, "This bully is always picking on me," and each

child has superficial abrasions. This is the third time this week Jonathan has been involved in an incident like this. As a SHP, what actions would you take?

Section 11

Epilepsy

According to the Epilepsy Foundation of America, epilepsy is a physical condition that occurs when there's a sudden, brief change in how the brain works. When brain cells aren't working properly, a person's consciousness, movement, or actions may be altered for a short time. These physical changes are called *epileptic seizures*. Epilepsy is therefore sometimes called a seizure disorder. Epilepsy affects people in all nations and of all races.

About two million Americans have epilepsy. Of the 100,000 new cases that develop each year, three quarters of them are in children and adolescents.

Some people can experience a seizure and not have epilepsy. For example, many young children have convulsions from fevers. These febrile convulsions are one type of seizure. Other types of seizures not classified as epilepsy include those caused by an imbalance of body fluids or chemicals or by alcohol or drug withdrawal. A single seizure doesn't mean that the person has epilepsy.

Symptoms

Although the symptoms listed below aren't necessarily indicators of epilepsy, it's wise to consult a doctor if someone you're working with experiences one or more of them:

- "Blackouts" or periods of confused memory.
- Episodes of unexplained unresponsiveness or staring.
- Involuntary movement of arms and legs.
- "Fainting spells" with incontinence or followed by excessive fatigue.
- Odd sounds, distorted perceptions, episodic feelings of fear that can't be explained.

Educational Implications

Students with epilepsy or seizure disorders are eligible for special education and related services under the Individuals with Disabilities Education Act (IDEA). Epilepsy is classified as "other health impaired" and an Individualized Education Program (IEP) would be developed to identify appropriate services. Some students may have additional conditions such as learning disabilities.

Seizures may interfere with the individual's ability to learn. If the individual has the type of seizure characterized by a brief period of fixed staring, he or she may be missing parts of what the teacher or supervisor is saying. It's important that the teacher or supervisor observe and document these episodes and report them promptly to family and nurses.

Depending on the type of seizure or how often they occur, some individuals may need additional assistance to help them keep up with others. Assistance can include adaptations in instruction, first aid instruction on seizure management to those that teach or work with the individual, and counseling, all of which should be written in the IEP.

It's important that teachers and school staff be informed about the individual's condition, effects of medication, and what to do in case a seizure occurs. Most family members find that a friendly conversation with teachers at the beginning of the school year is the best way to handle the situation. Even if an individual has seizures that are largely controlled by medication, it's still best to notify those teaching or working with the individual about the condition.

School and work personnel and the family should work together to monitor the effectiveness of medication as well as any side effects. If an individual's physical or intellectual skills seem to change, it's important to tell the doctor. There may also be associated hearing or perception problems caused by the brain changes. Written observations of both the family and school staff will be helpful in discussions with the individual's doctor.

Children and youths with epilepsy must also deal with the psychological and social aspects of the condition. These include public misperceptions and fear of seizures, uncertain occurrence, loss of self-control during the seizure episode, and compliance with medications. To help individuals feel more confident about themselves and accept their epilepsy, the school or work environment can assist by providing epilepsy education programs for staff or workers and students, including information on seizure recognition and first aid.

Individuals can benefit the most when the family, work and school are working together.

From *General Information about Epilepsy*, National Information Center for Children and Youth with Disabilities (NICHCY), Washington, DC.

First Aid for Seizures

About Seizures

There are many types of seizures – some more common than others. It's important that a person's seizure type be accurately identified so that a physician may, if necessary, prescribe the

proper anti-convulsant medication and provide guidance suitable to the person's condition and life-style.

Seizures can be *generalized*, meaning that all brain cells are involved. One type of generalized seizure consists of a convulsion with a complete loss of consciousness. Another type looks like a brief period of fixed staring.

Seizures are *partial* when those brain cells not working properly are limited to one part of the brain. Such partial seizures may cause periods of "automatic behavior" and altered consciousness. This is typified by purposeful looking behavior, such as buttoning or unbuttoning a shirt. Such behavior, however, is unconscious, may be repetitive, and is usually not recalled.

Among the seizure types seen most frequently are generalized tonic-clonic (grand mal) seizures, complex partial seizures, and absence (petit mal) seizures. In each of these types, the person experiencing the seizures loses consciousness either completely or partially. Properly administered first aid, where needed, can be very helpful.

Remember that there's no way to stop a seizure once it has started. The person's medication will not help: the seizure must be allowed to run its course. The principal reason for first aid measures is to keep the person from suffering any injury. Do not be concerned if, in a tonic-clonic seizure, the person cries out; he or she isn't in pain: the sound is a result of withheld air rushing out of the lungs.

Above all, stay *calm*. Your reassurance will be a comfort when the seizure is over. If the person has a series of seizures in quick succession without regaining consciousness or if a tonic-clonic seizure lasts more than five to ten minutes, a doctor should be called or the person should be taken to a hospital staffed and equipped to manage this situation.

Recognizing Generalized Tonic-Clonic (Grand Mal) Seizures

Symptoms of the tonic phase include:

- Sudden loss of consciousness
- Falling
- Involuntary outcries
- Muscle stiffening
- Temporary loss of ability to breathe

Symptoms of the clonic phase include:

- Alternate periods of muscle spasm and relaxation
- Possible cheek or tongue biting with bleeding
- Foamy salivation
- Cessation of breathing for a few seconds (the person may turn slightly blue)

The usual length of a tonic-clonic seizure is one to three minutes.

Characteristics of the post-seizure phase include:

- Resumed breathing
- Regained consciousness
- Temporary confusion and/or sleepiness
- Possible vomiting or loss of bladder or bowel control

What You Can Do to Help During or After a Seizure

- Try to cushion falls.
- Help the person to a lying position, preferably on his or her side to keep the airway open.
- Change the person's position by pushing or pulling the body trunk, not the limbs, because shoulder dislocations may sometimes occur.
- Remove any eyeglasses.
- Loosen tight clothing.
- Place something soft or a pillow under the head.
- Remove furniture or other objects from the immediate area.
- If possible at the beginning of a seizure (but *only* at the beginning), remove any dentures or other removable dental work.
- Don't try to restrain the individual's movement. The seizure will run its course. Attempts to restrain movement may cause injury.
- Remain with the person. Don't leave to get help – your presence may be necessary. It will be reassuring when the person awakens.
- *Never force anything into the mouth.* Attempting to pry apart firmly closed jaws may cause more injury than the seizure itself.
- Assist the individual's breathing. If the person is lying on his or her back, turn the person on his or her side after the convulsions have stopped. This will allow the tongue to return to its normal position, if it has fallen toward the throat and blocked breathing. It will also permit accumulated saliva to drain from the mouth. Do not attempt to clear the person's airway; breathing returns on its own as the seizure passes.
- Discourage premature activity. Don't try to make the person swallow liquids during the seizure or immediately afterwards: there's a possibility of choking. Don't rush the person into standing or walking while the post-seizure confusion remains. The person will eventually get up without encouragement.

Complex Partial Seizures

Symptoms of Complex Partial Seizures (Psychomotor, Temporal Lobe)

- Confusion, impaired awareness of surroundings; aimlessness.
- "Automatic" movements (pacing, hand rubbing, picking at clothing, lip smacking, or chewing motions).
- Possibly drunk or drugged appearance.
- Person may struggle if restraint is attempted.
- Lasts two to four minutes.
- May progress to generalized seizures.

First Aid Measures

- Stay with the person.
- Guide gently to protect from injury.
- Do not attempt to impede movements, as the person may struggle or fight.
- Let seizure run its course.
- Remain with person until consciousness is fully recovered.
- Let person rest or sleep until he or she feels well again.

Absence Seizures

Symptoms of Absence (Petit Mal) Seizures

- Very short; end rapidly.
- Few seconds of lost consciousness; often mistaken for day-dreaming.
- Possible staring, eye blinking, or facial twitching.
- Person doesn't generally fall.
- Person has no awareness of episode.
- Most common in children ages six to fourteen.

First Aid Measures

None are needed, but the person's physician should be notified of the seizure's occurrence.

From First Aid for Epileptic Seizures: A Guide for Parents, Teachers, and Friends, Epilepsy Foundation of America, Information Service, 1992.

Why This Information is Important to the Health Paraprofessional

The health paraprofessional may be called upon to direct others or lead in first aid procedures during a seizure. The health office

should also be the place where information is kept on individuals who have seizures and their needs. Know the characteristics of the various types of seizures. It's very important for you as the paraprofessional to be familiar with the procedures in case of seizure and for you to be a *calm* and knowledgeable resource to others in the environment.

Case Study

Candy is a six year old who has seizures. When she entered first grade this fall, her parents sat down with the school health nurse and her teacher and explained Candy's needs. Candy's seizures are a result of an early childhood accident on the playground. She has petit mal seizures fairly frequently, but she handles them without anyone knowing, for the most part, that she has had a seizure. The teacher and staff need to know that her apparent inattentiveness, may, however, be the result of these seizure. Candy is able to monitor and maintain herself except when she is overly tired. Then she is much more likely to having grand mal seizures. The parent, the teacher, the school health nurse and you sit down to come up with an IHP to address Candy's needs. Make suggestions as to what you think should be included in that IHP. Do you have enough information? Are there additional questions you need to ask? Do other staff people need to be involved and/or informed about Candy? If so, who? Make suggestions in a small group about how you would address Candy's IHP. Be prepared to discuss your ideas in the larger group.

Section 12

Hemophilia

Hemophilia is a hereditary blood clotting disorder which occurs most often in males, although a few cases have been diagnosed in females. It's caused by the inactivity or absence of one of several blood proteins necessary for clotting. There are about 20,000 males with hemophilia in the United States, an estimate which doesn't include many mild cases that remain undiagnosed until patients experience excessive bleeding after major trauma or surgery. Hemophilia occurs in one out of every 4,000 live male births. This population is expected to continue to grow, as medical advances have enabled the person with hemophilia to approach a normal life expectancy. It affects people of all races, nationalities, and economic levels. The prevalence of von Willebrand's disease, which occurs in males as well as females, may be as high as that for hemophilia.

A male with hemophilia cannot pass the disease on to his sons.

However, all of his daughters will be genetic carriers and can pass hemophilia on to succeeding generations. Women may carry the gene for hemophilia, but rarely have symptoms of the disease: mothers with apparently normal clotting ability may pass hemophilia on to their sons. In most instances, there's a known family history of hemophilia. As many as one third of newly discovered cases, however, have occurred in families without a history of this disorder. Von Willebrand's disease and other clotting disorders have different patterns of inheritance.

Hemophilia is classified by its level of severity – mild, moderate, and severe, which in turn is determined by the percentage of active clotting factor in the blood. Persons with severe hemophilia have less than one percent of the normal level of active clotting factor present in their blood.

The clotting disorders included in the term hemophilia are Hemophilia A (Classical Hemophilia, Factor VIII deficiency), and Hemophilia B (Christmas disease, Factor IX deficiency), and Von Willebrand's disease. Other rare clotting disorders may have similar symptoms, but aren't usually termed hemophilia. All of these disorders are included within programs of The National Hemophilia Foundation.

What Happens When a Person with Hemophilia Bleeds?

A person with hemophilia or Von Willebrand's disease doesn't bleed faster than anyone else, but may bleed for a longer time. Contrary to common opinion, people with hemophilia don't bleed to death from minor external wounds. Minor cuts are easily treated, much as they are in the person without hemophilia.

The major problem for the person with hemophilia is uncontrolled internal bleeding which can begin spontaneously without apparent cause. If internal bleeding is not quickly stopped with appropriate treatment, it will result in pain and swelling. Over a period of time, bleeding into joints and muscles can cause permanent damage leading to chronic pain and arthritis.

Treatment

The person with hemophilia is treated each time he or she experiences internal bleeding by infusing a clotting factor derived from human blood. This infused clotting factor stops the bleeding but remains active in his blood for less than a day. More serious bleeding episodes require repeated infusions of clotting factor until the bleeding is controlled. It's important to administer clotting factor as soon as internal bleeding begins in order to reduce the chances of permanent damage. Although there is effective treatment, there's presently no cure for hemophilia. A child born with the disease will have hemophilia throughout his life.

The treatment of hemophilia is expensive. The cost of blood products and other hemophilia related medical expenses varies from person to person. Studies have shown that the average cost to an individual is approximately \$10,000 a year. On occasion, complications of hemophilia, such as major surgery, have caused annual medical expenses to exceed \$100,000. The costs for safer and purer clotting factors now under development may increase treatment expenses.

Complications of Treatment

Hepatitis viruses can be transmitted by blood products, including clotting factor concentrates. These viruses lead to very mild chronic infections in most persons with hemophilia, but can progress to severe liver disease in some people.

During the early 1980s, most clotting factor became contaminated with the virus that causes acquired immunodeficiency syndrome (AIDS). As a result, many persons with hemophilia were exposed to this virus, termed Human Immunodeficiency Virus (HIV), and some individuals developed AIDS. The majority of persons with hemophilia have *not* contracted AIDS; however, the potential to develop the disease is still a major concern to those who were exposed to HIV in the early 1980s. Blood products available today are much safer because blood donors are screened, their blood is tested for evidence of HIV infection, and products are heat treated to destroy any virus which might not have been detected. For those who weren't exposed to HIV, these safety measures have eliminated the risk of infection from clotting factors.

Advances in the Treatment of Hemophilia

Beginning in the 1960s, the treatment of hemophilia radically changed when clotting factors became available in concentrated form. Improved treatment continued through the 1970s, with development of comprehensive care in regionalized hemophilia treatment centers throughout the United States. As a result, the quality of life for the person with hemophilia has improved dramatically. People with hemophilia and their families have been taught to administer clotting factor at home, work, and school. Home therapy allows for early treatment and frees the patient and his family from complete dependence on the hospital. With adequate clotting factor and careful management, most people with hemophilia may safely undergo complex dental procedures and major surgery at hemophilia treatment centers.

Counseling and education have substantially enhanced the potential for people with hemophilia to lead independent and productive lives. Genetic counseling has expanded considerably due to these recent advances in genetic testing. Carriers of the hemophilia gene can now be detected with a high degree of certainty, and a fetus with hemophilia can now be identified early in pregnancy.

The advances in hemophilia care since the 1970s have led to dramatic human and economic benefits:

- 74% reduction in unemployment.
- 73% reduction in days lost from work or school.
- 83% reduction in hospitalization.
- 74% reduction in costs of care.

The National Hemophilia Foundation's goals for the future include finding a cure through research; improving the safety and efficacy of clotting factors; developing treatments for HIV and AIDS; providing optimal health care for hemophilia at lower costs; educating the public; and providing adequate psycho-social support to families.

Very recent advances in immunology and genetic engineering have resulted in highly purified and virus-free human and synthetic (recombinant-DNA produced) clotting factors which are now undergoing clinical testing. These new technology products are the first step toward a cure for hemophilia. Alternative treatment methods are being explored as well, such as the use of a synthetic hormone called DDAVP to treat some patients with von Willebrand's disease and mild hemophilia.

Adapted from materials by the National Hemophilia Foundation, New York, NY.

Why This Information is Important for the Health Paraprofessional

Persons with hemophilia may require special care from you, especially in the case of accidents during the day. Make sure you know who has this condition in your setting and what special care they may need.

Section 13

Lupus

Lupus is a chronic inflammatory disease that can affect various parts of the body, especially the skin, joints, blood, and kidneys. The body's immune system normally makes proteins called antibodies to protect the body against antigens – viruses, bacteria, and other foreign materials. In an autoimmune disorder such as lupus, the immune system loses its ability to tell the difference between antigens and its own cells and tissues. The immune system then makes antibodies directed against "self." These antibodies, called *auto-antibodies*, react with the "self" antigens to form immune complexes. The immune complexes build up in the tissues and can

cause inflammation, injury to tissues, and pain.

For most people, lupus is a mild disease affecting only a few organs. For others, it may cause serious and even life-threatening problems. More than 16,000 Americans develop lupus annually. Approximately 500,000 Americans have been diagnosed with lupus.

The idea that lupus is generally a fatal disease is one of the gravest misconceptions about this illness. In fact, the prognosis of lupus is much better today than ever before. Although there's currently no cure, current methods of therapy have made deaths from lupus very uncommon: up to ninety percent of people with lupus can live relatively normal lives for more than ten years after diagnosis. Most people with lupus rarely require hospitalization, especially if they follow their treatment plans.

Types of Lupus

There are three types of lupus: *discoid*, *systemic*, and *drug-induced*.

Discoid Lupus

Discoid lupus is always limited to the skin. It's identified by a rash that may appear on the face, neck, and scalp, and is diagnosed by examining a biopsy of the rash for abnormalities that aren't found in skin without the rash. Because discoid lupus doesn't generally involve the body's internal organs the ANA test, used to detect systemic lupus, may be negative in patients with discoid lupus. However, in a large number of patients with discoid lupus, the ANA test is positive, but at a low level or "titer."

In approximately ten percent of patients, discoid lupus can evolve into the systemic form of the disease, which can affect almost any organ or system of the body. This cannot be predicted or prevented. Treatment of discoid lupus will not prevent its progression to the systemic form. Individuals who progress to the systemic form probably had it at the outset, with the discoid rash as their main symptom.

Systemic Lupus

Systemic lupus is usually more severe than discoid lupus and can affect almost any organ or system of the body. For some people, only the skin and joints will be involved. In others, the joints, lungs, kidneys, blood or other organs and/or tissues may be affected. Generally, no two people with systemic lupus will have identical symptoms. Systemic lupus may include periods in which few, if any, symptoms are evident ("remission") and other times when the disease becomes more active ("flare"). Most often when people mention "lupus," they are referring to the systemic form of the disease.

Drug-induced Lupus

Drug-induced lupus occurs after the use of certain prescribed drugs. The symptoms of drug-induced lupus are similar to those of systemic lupus. The drugs most commonly connected with drug-induced lupus are hydralazine (used to treat high blood pressure or hypertension) and procainamide (used to treat irregular heart rhythms). However, not everyone who takes these drugs will develop drug-induced lupus. Only about four percent of the people who take these drugs will develop the antibodies suggestive of lupus. Of those four percent, only an extremely small number will develop overt drug-induced lupus. The symptoms usually fade when the medications are discontinued.

Causes of Lupus

The direct cause or causes of lupus is unknown, but there *are* environmental and genetic factors involved. Some of the environmental factors that may trigger the disease are infections, antibiotics (especially those in the sulfa and penicillin groups), ultraviolet light, extreme stress, and certain drugs.

Although lupus is known to occur within families, there's no known gene or genes which are thought to cause the illness. Only ten percent of lupus patients will have a close relative who already has or may develop lupus. Statistics show that only about five percent of the children born to individuals with lupus will develop the illness.

Lupus is often called a "woman's disease" despite the fact that many men are affected. Lupus can occur at any age, and in either sex, although it occurs ten to fifteen times more frequently among adult females than among adult males. The symptoms of the disease are the same in men and women. People of African, American Indian, and Asian origin are thought to develop the disease more frequently than Caucasians, but the studies that led to this result are small and need corroboration.

Hormonal factors may explain why lupus occurs more frequently in females than in males. The increase of disease symptoms before menstruation and/or during pregnancy supports the belief that hormones, particularly estrogen, may be involved. However, the exact hormonal reason for the greater prevalence of lupus in women, and the cyclic increase in symptoms, is unknown.

Symptoms

Although lupus can affect any part of the body, most patients experience symptoms in only a few organs. The table below is a list of the most common symptoms of people with lupus.

Symptom	Percentage
Achy joints (arthralgia)	95
Fever over 100° F (38° C)	90
Arthritis (swollen joints)	90
Skin rashes	74
Anemia	71
Kidney involvement	50
Chest pain on deep breathing (pleurisy)	45
Butterfly-shaped rash across the cheeks and nose	42
Photosensitivity	30
Hair loss	27
Raynaud's phenomenon (fingers are white/blue in cold)	17
Seizures	15
Mouth or nose ulcers	12

Flares

What triggers an attack of lupus in a susceptible person? For some, exposure to the sun causes sudden development of a rash and then possibly other symptoms. In others a cold or a more serious infection doesn't get better and then complications arise. These complications may be the first signs of lupus. In still other cases, a drug taken for some illness produces the signaling symptoms. In some women, the first signs develop during pregnancy. In others, they appear soon after delivery. Many individuals cannot remember or identify a specific factor. Obviously, many seemingly unrelated factors can trigger the onset of the disease.

People with lupus should learn to recognize early symptoms of disease activity to help their physicians know when a change in therapy is needed. Regular monitoring by laboratory tests can also be valuable because noticeable symptoms may occur only after the disease has significantly flared. Changes in blood test results may indicate the disease is becoming active even before the patient develops symptoms. Generally, the earlier such flares are detected the more easily they can be controlled. Early treatment may also decrease the chance of permanent damage and reduce the time one must remain on high doses of drugs.

Diagnosis

Because many lupus symptoms mimic those of other illnesses, are sometimes vague, and may come and go, lupus can be difficult to diagnose. Diagnosis is usually made by a careful review of the patient's entire medical history coupled with an analysis of the results obtained in routine laboratory tests and some specialized tests related to immune status. There's currently no single test to determine if a person has lupus. To assist the physician in the di-

agnosis of lupus, the American Rheumatism Association issued a list of eleven symptoms or signs that help distinguish lupus from other diseases (see the table below). A patient should have four or more of these symptoms to suspect lupus. The symptoms don't all have to occur at the same time.

Criterion	Definition
Malar Rash	Rash over the cheeks
Discoid Rash	Red raised patches
Photosensitivity	Reaction to sunlight, resulting in the development of or increase in skin rash
Oral Ulcers	Ulcers in the nose or mouth: usually painless
Arthritis	Nonerosive arthritis involving two or more peripheral joints
Serositis	Pleuritis or pericarditis
Renal Disorder	Excessive protein and/or cellular casts in the urine.
Neurologic Disorder	Seizures and/or psychosis in the absence of drugs or metabolic disturbances which are known to cause such effects.
Hematologic Disorder	Hemolytic anemia or leukopenia (white blood count below 4,000/mm ³) or lymphopenia (less than 1,500 lymphocytes/mm ³) or thrombocytopenia (less than 100,000 platelets/mm ³).
Note: <i>The leukopenia and lymphopenia must be detected on two or more occasions. The thrombocytopenia must be detected in the absence of drugs known to induce it.</i>	
Immunologic Disorder	Positive LE prep, anti-DNA, or anti-Sm test, or false positive syphilis test (VDRL).
Antinuclear Antibody	Positive test for anti-nuclear antibodies (ANA) in the absence of drugs known to induce it.

Testing

The first laboratory test devised was the LE (lupus erythematosus) cell test. Unfortunately, the LE cell test is not specific for systemic lupus: it can also be positive in up to twenty percent of patients with rheumatoid arthritis, in some patients with other rheumatic

conditions like Sjogren's syndrome or scleroderma, in patients with liver disease, and in persons taking certain drugs (such as procainamide, hydralazine, and others).

The immunofluorescent anti-nuclear antibody (ANA, or FANA) test is more specific for lupus. It's positive in virtually all patients with systemic lupus, and is the best diagnostic test for systemic lupus currently available. If the test is negative, the patient will likely not have systemic lupus. Yet because it *can* be positive in conditions other than lupus, the results of the ANA test have to be interpreted in light of the individual's medical history, as well as the current clinical signs and symptoms.

New tests, such as the anti-DNA antibody, anti-Sm antibody, anti-RNP antibody, and the anti-Ro antibody tests, have been developed which are very helpful in diagnosis.

Physicians will sometimes also perform skin biopsies of both the patient's rashes and his or her normal skin. These biopsies can help diagnose systemic lupus in about seventy-five percent of patients.

The interpretation of all these positive or negative tests, and their relationship to symptoms, is frequently difficult. A test may be positive one time and negative another time, reflecting the relative activity of the disease or other variables. When questions cannot be resolved, consult an expert in lupus.

When someone has many symptoms and signs of lupus and has positive tests for lupus, physicians have little problem making a correct diagnosis and initiating treatment. However, a more common problem occurs when an individual has vague, seemingly unrelated symptoms of achy joints, fever, fatigue, or pains. Some doctors may think the person is neurotic. Others may try different drugs in the hope of suppressing the symptoms. Fortunately, with growing awareness of lupus, an increasing number of physicians will consider the possibility of lupus in the diagnosis.

Treatment

For the vast majority of people with lupus, effective treatment can minimize symptoms reduce inflammation, and maintain normal bodily functions.

Preventive measures can reduce the risk of flares. For photosensitive individuals, avoiding excessive sun exposure and/or the regular application of sunscreens will usually prevent rashes. Regular exercise helps prevent muscle weakness and fatigue. Immunization protects against specific infections. Support groups, counseling, talking to family members, friends, and physicians can help alleviate the effects of stress. Needless to say, negative habits like smoking, excessive consumption of alcohol, too much or too little prescribed medication, or postponing regular medical checkups, are hazardous to people with lupus.

Treatment approaches are based on the specific needs and

symptoms of each person. Because the characteristics and course of lupus may vary significantly, it's important to emphasize that a thorough medical evaluation and ongoing medical supervision are essential to ensure proper diagnosis and treatment.

Medications are often prescribed for people with lupus depending on which organ(s) are involved, and the severity of involvement. Effective patient-physician discussions regarding the selection of medications, their possible side effects, and any changes in dosage are vital. Commonly prescribed medications include:

- **Non-Steroidal Anti-Inflammatory Drugs (NSAIDs):** These medications are prescribed for a variety of rheumatic diseases, including lupus. The compounds include acetylsalicylic acid (aspirin), ibuprofen, naproxen, indomethacin, sulindac, tolmetin, and others. These drugs are usually recommended for muscle and joint pain and arthritis. Aspirin may cause stomach upsets for some people. The other NSAIDs work in the same way as aspirin, but tend to be less irritating to the stomach and often require fewer pills per day to have the same effect.
- **Acetaminophen:** Acetaminophen (e.g., Tylenol) is a mild analgesic that can often be used for pain. It has the advantage of less stomach irritation than aspirin, but it's not nearly as effective at suppressing inflammation as aspirin.
- **Corticosteroids:** Corticosteroids (steroids) are hormones normally produced in small quantities by the adrenal gland that have anti-inflammatory and immunoregulatory properties. This hormone controls a variety of metabolic functions in the body. Because steroids have a variety of side effects, such as weight gain, acne, easy bruising, osteoporosis, high blood pressure, cataracts, increased risk of infection and stomach ulcers, the dose has to be regulated. Side effects occur more frequently when steroids are taken over long periods of time at high doses.
- **Anti-malarials:** Chloroquine (Aralen) or hydroxy chloroquine (Plaquenil), commonly used in the treatment of malaria, may also be very useful in some individuals with lupus. They are most often prescribed for skin and joint symptoms of lupus.
- **Cytotoxic Drugs:** Azathioprine and cyclophosphamide are in a group of agents known as cytotoxic or immunosuppressive drugs which act in a similar manner to the corticosteroid drugs. The side effects of these drugs include anemia, low white blood cell count, and increased risk of infection. Their use may also predispose an individual to developing cancer.

Nutrition and Diet

There have been suggestions about various foods and the treatment of lupus. However these diets have been used only in animals

with limited success and should not become the main stay of a patient's diet.

Information adapted from materials by the Lupus Foundation of America, Inc., Rockville, MD.

Why This Information is Important for the Health Paraprofessional

Individuals with lupus may need your support during the day if they have a flare up. You should also know the symptoms in case you begin seeing someone regularly complaining of symptoms that may be early signs of the disease.

Section 14

Neurological Impairments

The following information is given as background information to help in the understanding of any of a number of neurological disorders in which individuals may need special assistance from the health paraprofessional. The first part provides background information into the neurological evaluation. You may be in planning meetings where the neurological report on an individual is discussed: the first part of this chapter is designed to give you a better idea of what that report means.

The second section gives information about head injuries. Head injuries are highlighted here because people who have had head injuries resulting in disability related conditions are becoming more and more prevalent. As medicine continues to improve and people survive more accidents that would previously been fatal, survivors are re-entering schools and work needing special medical assistance.

The Neuropsychological Evaluation

The diagnosis of brain injury can frequently be aided by clinical neuropsychology, a branch of psychology which concerns itself with cognitive impairments from brain injury – impairments in thinking and reasoning, language processes, memory, attention, and organization of behavior.

Neuropsychological evaluation employs a wide range of objective tests designed to assess thinking and reasoning abilities (both verbal and non-verbal); memory; attention and concentration; the ability to understand and produce written and spoken language; and sensory motor abilities. Comparisons are made between the performances of groups of people with and without brain injuries

and patterns of impaired functioning can be identified. When these patterns make sense in terms of what is known about the workings of different areas of the brain, conclusions can be reached about probable brain damage and its location even when "hard" signs are lacking. The symptoms produced by the more diffuse, microscopic lesions of concussion are more difficult to interpret than those caused by severe localized brain injuries. Still, there may be a patterning or severity which strongly implies organic brain damage.

Signs of Brain Injury

The cognitive signs of organic brain injury are as diverse as the human mind itself. Frequently, there is impairment of memory of new events and also for intentions because the brain regions subserving these functions (in the temporal and frontal lobes) are extremely susceptible to injury due to bony protrusions inside the skull, no matter where the blow. Also common are difficulties with sustained concentration, and the person may become quite distractible and digressive in conversation. Language problems can also be seen as a difficulty in finding words, slowed or slurred speech, or problems in understanding conversation. Language difficulties usually suggest damage to left cerebral hemisphere. Other problems come about from damage to the right hemisphere. Right hemisphere injuries commonly involve problems in understanding spatial relationships, so that a person may not be able to build things, or draw simple representations, or may become easily lost in the environment.

A third class of problems affects the organization of behavior. Difficulties staying with a task, in making plans or in solving problems are often seen in frontal-lobe injuries. Sometimes a brain injury will show itself in emotional outbursts or in difficulty with tolerating frustration.

Treatment of Cognitive Problems

Until recently, it was believed that all brain damage is irreversible and that significant recovery or organic cognitive impairment was rare. Both of these beliefs have been challenged by recent research and by new developments in treatment. The brain, it appears, does possess remarkable abilities to recover after injury, and it can continue to recover over a period of many years. Part of the recovery seems to involve the reorganization of the brain to accommodate for lost function – intact areas taking over for damaged areas. Even re-growth of nerve tissue can occur under some conditions. Specific simulation and retraining appears to be essential in supporting these processes. Even where re-growth doesn't occur, helping an individual understand and compensate for lost abilities is beneficial, since the nature of a brain injury is often hidden from the individual's and the family's awareness.

A new treatment advance, emphasizing these principles, is cog-

nitive rehabilitation – a marriage of cognitive psychology, neurology, remedial education, and psychotherapy. Employing exercises to simulate arousal and concentration to prod and compensate for poor memory, to retrain thinking and problem solving, and to re-teach social skills, cognitive rehabilitation programs have helped many people with brain injuries return to more satisfying and useful lives.

Brain-injury treatment programs employing cognitive rehabilitation are just beginning to make an impact, and there are now several in various parts of the country. Many hospitals have outpatient rehabilitation services which accomplish similar purposes. Treating a person with a cognitive impairment from brain injury as if the main problem were depression or anxiety can only confuse an already confused person and add feelings of guilt and hopelessness to the existing problem. With increasing medical and legal awareness about the organic basis of post-concussional syndromes, it's likely that for many of these persons better and more appropriate treatment can be offered.

Adapted from "Head Injury Symptoms: Brain vs. Neurosis", Charles Furst, Ph.D., Los Angeles Trial Lawyers Association.

Head Injury and Traumatic Brain Injury (TBI)

There are numerous types of traumatic brain injuries, among which are concussion, brain stem injury, closed head injury, cerebral hemorrhage, depressed skull fracture meningitis (from a fracture that exposes brain to germs), open head injury (foreign objects), anoxia, aneurysm, and stroke.

Head injury can happen to anyone anytime, and while no one is immune, statistics show that twice as many males are injured as females and that males sixteen to twenty-four years of age incurred more head injuries than any other group. Half of all head injuries are caused by motor vehicle accidents. Other causes of head injuries are falls, sports injuries, near drownings, industrial accidents, assault, and gun shot wounds.

According to the National Head Injury Foundation, two million head injuries occur each year in the United States. Of this group:

- 70,000–100,000 persons die as a result of a head injury.
- 500,000 persons require hospitalization as a result of a head injury.
- 70,000–90,000 suffer life-long physical, intellectual, and psychological disabilities as a result of a head injury.

This estimate includes head injuries categorized from mild to severe. Although exact data detailing the morbidity and modality from traumatic head injury in this country are unavailable, a num-

ber of studies have allowed estimates to be made which document the seriousness of the problem.

Serious head injuries usually result in prolonged loss of consciousness or coma which may be brief, lasting only a few minutes, or may extend to days or weeks. If the period of coma is brief, recovery to full or nearly full function is likely; but as time in coma lengthens, emergence to a fully alert state can take a long time. Intellectual impairment, speech problems, behavioral disorders and other related physical disabilities can become realities. The individual and his or her family face a lengthy period of rehabilitation that can extend for years. Most head injuries result from accidents, but similar problems can result from conditions such as encephalitis, lack of oxygen to the brain, and cerebral hemorrhage.

Typical Impairments of Individuals with Head Injury

The typical impairments you may encounter in individuals with head injury fall into three broad categories: physical, cognitive, and psycho-social-behavioral-emotional impairments. Any or all of these impairments may occur in varying degrees. A severely impaired individual's impairments may encompass all of the below, but it's important to note that with early and ongoing therapeutic intervention, the severity of some of these symptoms might decrease. Intellectual ability might not improve, but social and behavioral aspects and memory could improve over long periods of time.

Types of physical impairments may be:

- Aphasia
- Hearing
- Hemiparesis
- Paraplegia
- Physical disability; orthopedic involvement
- Seizures
- Spasticity
- Visual impairment

Types of cognitive impairments may be:

- Attention
- Concentration
- Headaches
- Judgment
- Lack of foresight
- Memory deficit (short & long-term)
- Perception
- Planning (sequencing difficulty)

Psycho-social-behavioral-emotional impairments may include:

- Agitation
- Anxiety
- Denial
- Depression
- Disinhibition
- Egocentricity
- Emotional lability
- Euphoria
- Fatigability
- Inability to cope
- Lack of motivation (inability to self-monitor)
- Lack of self-esteem
- Restlessness
- Sexual dysfunction

Factors Affecting the Outcome of Head Injury

- Age at the time of the brain injury
- Location of the areas of the brain dysfunction
- Severity of the brain damage and the length of coma
- Time lapsed since the injury occurred
- Preexisting intellectual skills
- Preexisting personality characteristics
- Type of environment since the injury
- Motivation for recovery
- Nature of the family constellation and involvement
- Rapid entry into a rehabilitation facility with programs for the rehabilitation of the head injured.

Treatment

Once the patient is out of coma, both he or she and the family must look forward to a long period of rehabilitation. Substantial gains can be expected over the first year, and additional improvements will occur for at least two to three years. Even those injured many years previously can make gains when placed in the proper therapeutic setting.

Predicting long-term outcome and degree of disability after serious head injury is much more difficult. It's true that the longer coma lasts, the greater the disability is likely to be. For all individuals surviving six hours or more of coma, over half will return to school, jobs, or independent living by a year after injury, although many will have some residual cognitive problems. Those coming

out of coma in the first day or two will do better than those remaining in coma a longer period of time, but one cannot predict with certainty what will happen in each individual case.

A great variety of rehabilitation and services are needed by individuals with brain injuries. New techniques of cognitive remediation, behavior modifications, and memory retraining are needed to advance the head injured individual from coma to community. They require opportunities like family counseling and support; legal and financial counseling; long-term rehabilitation centers; vocational training and day programs; community residences and transitional living; and educational opportunities. Examples of resources include the Minnesota Head Injury Association and the Department of Human Services.

Why This Information is Important for the Health Paraprofessional

Many individuals in high school, post-secondary education, and in employment have had accidents, injuries, or illnesses resulting in brain injury. Depending on the involvement, the individual may need support for feeding, toileting, accommodations, medications, or in case of seizure activity. It's important to know the characteristics and challenges that face these individuals so you can begin to understand and recognize behaviors that may be a result of the brain injury and those that may be personality traits. This can help you in helping the individuals through the frustrations and difficulties that often accompany the adjustment of individuals to their own (new) limitations as a result of the brain injury.

Section 15

Primary Immune Deficiency

When a defect in the immune system is inherited (carried through the genes), it's called a *primary immune deficiency*. More than seventy primary immune deficiency diseases, ranging widely in severity, have been identified to date. Among these seventy-plus primary immune deficiency diseases are IgA deficiency, hypogammaglobulinemia – also called *common variable immune deficiency* (CVI) – IgG subclass deficiency, complement deficiency, chronic granulomatous disease (CGD), X-linked agammaglobulinemia (XLA), and severe combined immunodeficiency (SCID), in which the body has virtually no immune defenses.

Primary immune deficiency affects as many as one person in five hundred and can strike males and females of all ages, though they frequently occur early in life. The more severe immunodeficiency diseases are detected most frequently in children.

It's important to remember that even though both involve the immune system, primary immune deficiency and acquired immune deficiency syndrome (AIDS) are very different and should not be confused with each other. Primary immune deficiency is inherited; AIDS, on the other hand, is acquired by contracting the HIV virus. The HIV virus is sometimes passed from a mother to her unborn child, but this is still an infectious, rather than a genetic, problem.

Though it's hoped that research efforts in primary immune deficiency and AIDS will at times benefit each other, they are still completely separate conditions where diagnosis and treatment are concerned.

Symptoms

Primary immune deficiency diseases don't have unique symptoms of their own. Rather, they appear as "ordinary" infections, often of the sinuses, ears, or lungs. These infections can be chronic — which means they keep coming back, sometimes frequently, and can be severe. They also tend to require prolonged recovery, and may respond poorly to a conventional course of antibiotics. They can also cause gastrointestinal problems or inflammation of the joints.

People with primary immune deficiency can have long periods of normal health, then suddenly be struck by high fevers, pneumonia, or any of the other problems noted below. The illnesses themselves are frightening, the lack of a definite diagnosis and treatment is frustrating, and "waiting for the next attack" can turn even the healthy periods into times of great anxiety.

Primary immune deficiency can result in:

- Infections of the type noted above, leading to frequent bouts of sinusitis, bronchitis, and pneumonia
- Thrush in the mouth after the first year of life
- Recurrent abscesses
- Meningitis
- Osteomyelitis
- Cellulitis

All these problems could have a number of causes, but when they occur the possibility that primary immune deficiency is present should be explored. Early diagnosis and treatment of primary immune deficiency disease is essential to prevent recurring infections from doing permanent damage. Unfortunately, the lack of unique symptoms causes these diseases to resemble a great number of other illnesses. Thus, families and doctors are often unaware that the troubling conditions they are dealing with are actually rooted in a defect of the immune system.

Diagnosis

Correct diagnosis begins with awareness of the signs discussed above. Once the condition is suspected, doctors can order blood tests and screenings to evaluate the function of the infection-fighting cells of the immune system. Because primary immune deficiency is genetic in nature, blood relations of patients are often examined. Sometimes an unborn fetus can be tested for a specific disease. Of course, tests should be ordered as soon as primary immune deficiency is suspected, so that treatment may begin quickly if a problem is present.

Treatment

Once a diagnosis is established, much can be done for people with immunodeficiencies. At a minimum, the recurring infections can be treated with low or moderate doses of appropriate antibiotics. These can help prevent permanent damage to the lungs and bronchial tubes, thus promoting the individual's long-term survival while improving the quality of life.

A more basic therapy is to supply, when appropriate, the gammaglobulin that in some diseases the body can not make on its own. Such immunoglobulin therapy is now accepted for a range of primary immune deficiency diseases.

Other new therapies include advanced pharmaceuticals such as the interleukins, PEG-ADA, and gamma interferon. Bone marrow transplants can help in some cases.

Adapted from materials from the Jeffrey Modell Foundation, Department A: New York, NY.

Why This Information is Important for the Health Paraprofessional

Because of the increase in this condition, it's important for paraprofessionals to know about the characteristics in case you may be called upon to support some of the individual needs that an individual may require. What would the SHP need to know when caring for someone with either acquired or genetic primary immune deficiency?

Section 16

Spina Bifida

Spina Bifida means *cleft spine*, which is an incomplete closure in the spinal column. In general, the three types of spina bifida – in increasing severity – are:

- **Spina Bifida Occulta:** One or more of the vertebræ (bones) of the spinal column has an opening without apparent damage to the spinal cord.
- **Meningocele:** The meninges, or protective covering around the spinal cord, has pushed out through the opening in the vertebræ in a sac called the “meningocele.” However, the spinal cord remains intact. This form can be repaired with little or no damage to the nerve pathways.
- **Myelomeningocele:** This is the most severe form of spina bifida, in which a portion of the spinal cord itself protrudes through the back. In some cases, sacs are covered with skin; in other, tissue and nerves are exposed. Generally, people use the terms *spina bifida* and *myelomeningocele* interchangeably.

Approximately forty percent of all Americans may have spina bifida occulta, but because they experience little or no symptoms, very few of them ever know that they have it. The other two types of spina bifida, meningocele and myelomeningocele, are known collectively as *spina bifida manifesta*, and occur in approximately one out of every thousand births. Of these infants born with spina bifida manifesta, about four percent have the meningocele form, while ninety-six percent have myelomeningocele form.

Symptoms

The effects of myelomeningocele, the most serious form of spina bifida, may include muscle weakness or paralysis below the area of the spine where the incomplete closure (or cleft) occurs, loss of sensation below the cleft, and loss of bowel and bladder control. In addition, fluid may build up and cause an accumulation of fluid in the brain (a condition known as hydrocephalus). A large percentage (seventy to ninety percent) of children born with myelomen-ingocele have hydrocephalus. Hydrocephalus is controlled by a surgical procedure called “shunting,” which relieves the fluid build-up in the brain. Hydrocephalus may occur without spina bifida, but the two conditions often occur together. If a drain (shunt) is not implanted, the pressure buildup can cause brain damage, seizures, or blindness.

Educational Implications

Although spina bifida is relatively common, until recently most children born with a myelomeningocele died shortly after birth. Now that surgery to drain spinal fluid and protect children against hydrocephalus can be performed in the first forty-eight hours of life, children with myelomeningocele are much more likely to live. Quite often, however, they must have a series of operations throughout their childhood. School programs should be flexible to accommodate these special needs.

Many children with myelomeningocele need training to learn to manage their bowel and bladder functions. Some require catheterization – the insertion of a tube to permit passage of urine. The courts have held that clean, intermittent catheterization is necessary to help the child benefit from and have access to special education and related services. Many children learn to catheterize themselves at a very early age. A successful bladder management program can be incorporated into the regular school day.

In some cases, children with spina bifida who also have a history of hydrocephalus experience learning problems. They may have difficulty with paying attention, expressing or understanding language, and grasping reading and math. Early intervention with children who experience learning problems can help considerably to prepare them for school.

Inclusion of a child with spina bifida into a school attended with non-disabled young people, sometimes requires changes in school equipment or the curriculum. Although student placement should be in the least restrictive environment, the day-to-day school pattern also should be as "normal" as possible. In adapting the school setting for the individual with spina bifida, architectural factors should be considered. Section 504 of the Rehabilitation Act of 1973 requires that programs receiving federal funds make their facilities accessible. This can occur through structural changes (for example, adding elevators or ramps) or through schedule or location changes (for example, offering a course on the ground floor).

Children with myelomeningocele need to learn mobility skills, and often require the aid of crutches, braces, or wheelchairs. It's important that all members of the school team and the parents understand the child's physical capabilities and limitations. Physical disabilities like spina bifida can have profound effects on a child's emotional and social development. To promote personal growth, families and teachers should encourage children, within the limits of safety and health, to be independent and to participate in activities with their non-disabled classmates.

Information provided by the National Information Center for Children and Youth with Disabilities, Washington, DC.

Treatment

The advent of the ventricular-atrial shunt and the spitz-Holter valve in the 1950s, as well as other recent medical developments, have improved the overall survival rate and increased the life expectancy of children with spina bifida. Today approximately eighty-five to ninety percent of newborns with spina bifida can expect to survive. As a result, today's health practitioners are becoming more and more aware of the need to develop treatment plans that encompass not only the child but also the adult with spina bifida. Additionally, a more holistic approach to health care is called for in order to treat what often become secondary physically or psycho-sociological disabilities.

The shunt procedures provided the first effective method of managing hydrocephalus. By the mid 1960s, this form of treatment became more common, as did the Sheffield Policy of early spinal closure, which was developed by Dr. Sharrard and his associates in Sheffield, England. The results, however, were universally encouraging. In 1971, a study of babies born with spina bifida treated at the Sheffield clinic showed that only forty percent had survived at least seven years and many of the survivors were severely handicapped.

For many physicians and researchers, these results stimulated increased attention and innovation in the management of spina bifida. Today, aggressive treatment policies continue. These treatment policies are supported in many different regions by multidisciplinary teams to monitor the urological, developmental, and psychological needs of the individual in addition to the neurosurgical and orthopedic needs which have long been recognized.

Information from the Spina Bifida Association of America, Washington, DC.

Emerging Issues in Spina Bifida: Secondary Disabilities

Special attention is needed in the identification and treatment of secondary disabilities in the adult population. The wide range of neurological damage and mobility impairment in the current generation makes it sometimes difficult to identify some of these secondary disabilities. Despite this difficulty in identifying secondary disabilities, the occurrence of problems such as tendonitis in the upper arms, due to wheelchair use, is quite common. As services for adults with spina bifida are developed, it will become easier to develop a tracking system that will further define these secondary disabilities. Consequently, treatment programs and methodology will become more sophisticated and accurate in providing these services.

More attention must be focused on the psychological and so-

cial development of young adults with spina bifida, if they are to become empowered as adults who can function independently within their non-disabled communities. Many recent studies, including the Spina Bifida Association of America's Adult Network Survey, clearly indicate the presence of emotional problems resulting from factors such as low self-esteem and lack of social skills training. The key factor in addressing this issue is of emotional problems in the teaching of the skills needed in adulthood to these young adults at an earlier age.

Recent findings indicate that mental health service needs of individuals with disabilities can be divided into six major problem areas: social/interpersonal, self; vocational/career, personal/emotional; marital/family, and sexual. These needs may be translated into such service provisions as peer counseling, rehabilitation counseling, respite care, individual therapy, family therapy, and social skills training. These service provisions may be used in the effort to build necessary skills to maximum independence.

Adapted from materials prepared by the Spina Bifida Association of America, Washington, DC.

Why This Information is Important for the Health Paraprofessional

The health paraprofessional may be called upon to help with special health needs of the individual with spina bifida. You may also be called upon to help train the individual in self-care. Additional support may be needed if the individual also has shunts and bowel care may also require your guidance. Be sure you get the background information on the individual and learn the best ways to handle the needs of the individual that are consistent with their personal care routine at home.

Section 17

Teenage Suicide and Depression

Many who live or work with teenagers have had contact with a child who has thought of suicide. Studies show that seven out of ten teens have thought of killing themselves. Suicide is the third leading cause of death among young people. Accidents are the leading cause but some of these "accidents" may be suicides. An estimated two million teenagers attempt to take their lives each year and about 6,000 succeed. The suicide rates for teens has tripled since 1950. Minnesota has a higher than average suicide rate.

Adolescence is a difficult time for teens and their families. It's pretty normal to have a lot of ups and downs, or changes in behavior and personality which makes telling that a teen is having serious problems difficult.

Causes

There's no one cause associated with youth suicides. Researchers feel that stress, primarily due to multiple losses or changes, builds up for a teen and creates feelings of hopelessness, helplessness, and worthlessness which become depression. Some of the most stressful situations are:

- Unrealistic self-expectations.
- Breaking up with a boy- or girlfriend.
- Changes in financial or marital status of parents.
- Trouble with teachers and/or grades.
- Moving to a new home or school.
- Experiencing some social embarrassment.

Other contributing factors may be:

- **Social Expectations:** Teens are very impressionable and suggestible, they may be influenced to think of suicide as a solution to their problems after being exposed to the suicide of a friend or relative, movies, or media coverage of suicides.
- **Isolation:** Many teens don't have adults around with whom they can communicate about their problems. Both parents often work or children live in single parent families, teachers aren't as available, even the church is not as involved in a family's life as in the past.
- **Feelings of Failure:** Children are expected to be self-sufficient and successful at an early age. Parents, teachers, and children themselves may have unrealistic expectations for their performance. Many are unable to deal with any failure. Teens are very *now* oriented. We live in a fast-paced world, and teens want solutions and changes right now, and don't have the life experience to realize that things can get better with time.
- **Increased Alcohol and Drug Abuse:** Children who are in emotional pain may self-medicate to end those feelings. This just lowers inhibitions, clouds the thinking and increases the chance of a successful suicide.
- **Sexual Orientation:** Gay and lesbian teens are often forced to be secretive about their sexual preferences. As a result, they often feel "different" and alone. Without resources to talk about these feelings, they are at an increased risk for attempting suicide.

Depression

Depression is a common emotional disorder that until ten years ago was thought to affect adults only. As many as six million adolescents and children suffer from major depression – much of it unrecognized. Many harmful behaviors linked to depression are attempts by an individual to deal with the psychological pain. These may be drug abuse, eating disorders, truancy, delinquency or suicide. Depression can be a fatal disease: between 1960 and 1980, the suicide rate for the population between fifteen and nineteen years of age increased by 136 percent.

Depression can be the result of several things, the most common of which is stress. Kids these days are under a lot of stress, and usually there are multiple stresses occurring at the same time. Other causes of depression can include a genetic predisposition or family history of mental illness, especially depression or alcoholism, or a physical or chemical imbalance in the person's body.

Each person's reaction to stress is very individual. Some can tolerate more stress than others and for a longer period of time. When kids feel stressed it's their body's way of telling them that something is going on and that they have to take care of themselves. Getting more exercise and rest, maintaining good nutrition, or talking to friends about what's happening (including an adult) are all good ways to help relieve these kinds of stress. If the stressors continue, it can develop into depression.

Symptoms of Depression

The two most important signs are that the individual feels sad, hopeless, worried, and irritable and lacks interest in activities such as sports, hobbies, family and friends, indicating a change in his or her normal routine.

Other signs are:

- Poor appetite and weight loss – or excessive eating and weight gain.
- Sleep disturbances: insomnia, early morning awakening or excessive sleeping.
- Unexpected outbursts of anger or crying.
- Loss of energy, persistent boredom, listlessness or fatigue.
- Diminished ability to concentrate, decline in quality of school work and grades.
- Agitation, or violent or rebellious behavior. The difference between "normal" adolescent rebellion and depression is based on the time, degree, and amount of deviation from the child's usual personality and behavior. The acting out behavior may be normal rebellion if the behavior is temporary – lasting from a day to a week or two – and if it's broken by periods of calm between outbursts. If the rebellion is consistent, in-

tense, protracted over a period of months, and drastic (i.e., out of character), the behavior may be a result of depression.

- Major personality change.
- Complaints about physical symptoms such as stomach ache or headache.
- Self-reproach or inappropriate guilt – child blames him- or herself for all that goes wrong.
- Inability to concentrate.
- Recurrent thoughts about death or any suicidal thoughts or behavior.
- Isolating from friends or family or not participating in usual activities that once were fun.
- Neglect of personal appearance.

Tips for Dealing with an Individual Who May Be Depressed

- **Be Informed:** It's important that you're aware of the signs and symptoms of stress and depression.
- **Talk:** Ask questions about what you're seeing. Convey a sense of support, understanding, and openness to talk about anything. Be aware that depressed individuals are often hypersensitive to criticism and very self-blaming.
- **Listen:** Kids often are experiencing so much pain that they can't talk about what's really bothering them. Listen with your eyes and ears. Kids will often deny there's anything wrong, but you can see that there is a problem.
- **Empathize:** Take a young person's problems seriously. We often tend to minimize their importance and view their problems through "adult eyes". We know that things will get better, but we've learned that through years of living. They don't have that skill yet.
- **Get Help:** Know what resources are available. If a child is showing signs of depression or has thoughts of suicide or harming themselves, don't leave the child alone; get immediate professional help.

If there isn't immediate danger, you can help by:

- Identifying the major problems.
- Examining possible solutions – concentrating on strengths and past problem-solving skills.
- Formulating a plan, setting it in action through small steps.
- Identifying other people the child may talk with.
- Getting the child future oriented – make some plans for the weekend or midweek fun activity.

The sooner depression is diagnosed the better the chances are it can be effectively treated. Severe depression doesn't go away quickly on its own, but given early and appropriate help depressed kids can live a normal and productive life.

Warning Signs of Suicidal Behavior

Verbal Warnings

These can be subtle or blatant and include talking about death, dying, or suicide, or saying statements such as:

- "I won't be a problem much longer"
- "It's no use to go on"
- "Everybody would be better off without me"
- "I think I'll just end it all."

Behavioral Warnings

Kids often can't communicate their pain, so it comes out in behaviors such as:

- Giving away cherished objects which may often have little monetary value.
- Composing suicide notes, writing about death.
- Sudden change to being cheerful after a depression – a person will often have made the decision to end their lives and now feel a sense of relief.
- Preoccupation with death or interest in guns or medications.
- Acting out or isolating.

If there isn't immediate danger, learn the resources available for crisis intervention or counseling – and get the person help.

Tips for Preventing Teen Suicides

- Let them know it's OK to feel depressed but not to contemplate suicide.
- Talk to them openly and honestly about what you're seeing, and listen to them with both your eyes and your ears.
- Agree to be there to help but never agree to keep a secret about what's going on.
- If the teen has a specific plan for self-harm and the means to carry it out, call the police. Don't leave the child alone.
- Realize that children *do* have problems and that some are killing themselves. Try to see the problem through their eyes rather than from an adult's perspective.
- Encourage teens to have at least three people they can talk to

about what bothers them and that one should be an adult.

- Help children to learn to accept failure; love and loving is not dependent on their success or good behavior.
- Be a role model for stress management.
- Don't make the means for suicide accessible. Don't keep loaded guns or lethal amounts of medications in your home.
- Know the resources available in your community before you need them and don't be ashamed or afraid to ask for help. Pride isn't more important than someone's life.

Adapted from facts sheets prepared by Fairview Riverside Mental Health Services, Minneapolis, MN.

Why This Information is Important for the Health Paraprofessional

The health office is where chronic complaints or issues are often seen. As the health paraprofessional, you need to be aware of the symptoms for teenage depression and suicide. What may seem like a nagging teenager to you may really be a teen reaching out for help. You may be the one individual the teen has approached. Record the times the individual comes to you and for what reason. Talk this over with the nurse. Make a recommendation if you feel there's something deeper going on. You may be the person who can save a teen's life. Do *not* underestimate your importance in this matter.

Case Study

Cory is a fifteen year old boy who drops in the health office with an array of slight ailments three or four times a week. There usually isn't anything you can do to help his physical condition (because he's pretty healthy) but you end up chatting with him. In the course of your conversations, you learn that Cory doesn't feel he's a very good student and that he has no real friends at school. He also tells you that home is a pretty sad place since his sister committed suicide two years ago (at the age of seventeen). You like Cory and feel concerned about him, but Cory has no real health care needs so you don't know what to do for him. Then suddenly, Cory stops coming to see you. What do you do? Should you express your concern to the LSN or other professionals in the building?

Section 18

Tourette Syndrome

Tourette Syndrome (TS) is a neurological multiple tic disorder which begins between the ages of two and sixteen and lasts throughout life. The symptoms of this developmental disability follow a waxing and waning course. TS isn't degenerative or fatal.

TS is caused by a chemical imbalance in the brain. The disorder appears to be genetic in about 85% of cases. In these families, one or more relatives have been identified with either milder tic conditions or Tourette Syndrome. This would indicate that mild tic conditions are probably a genetic continuum of one disorder, and TS is the most severe end of that spectrum.

A number of children have been identified with stimulant induced TS. Stimulant medications prescribed to hyperactive children (i.e., Ritalin, Cylert, Dexedrine, etc.), can sometimes precipitate TS in predisposed children according to the Food & Drug Administration (FDA).

Symptoms

Motor Symptoms

TS is characterized by multiple involuntary tic movements, the most common being rapid eye blinking, shoulder shrugging, facial twitches, head, arm or leg jerking. These repetitive muscular movements are commonly misinterpreted as "nervous habits" or a behavioral abnormality. TS tics and twitches always get worse under stress; they may lessen or disappear for short periods of time during non-anxious focused attention to a task or activity.

Vocal Symptoms

Motor symptoms are combined with uncontrollable vocalizations such as repeated throat clearing, grunting, sniffing or hissing. These symptoms can also be misinterpreted as a "nervous cough" or "bad habits." In more severe cases vocalizations can be quite loud and disturbing such as shrieking, barking, and/or abrupt outbursts of sounds or words. In thirty percent of cases people with TS will get coprolalia, which is involuntary outbursts of obscene words. Other speech problems can occur including echolalia (repeating the words of others), palilalia (repeating one's own words), stuttering, speaking in uneven rhythms, accenting syllables, etc.

Behavioral Symptoms

Behaviors commonly associated with TS may include attention deficit, hyperactivity, impulsivity, learning disabilities, imitating

movements and gestures of other people, and/or obsessive-compulsive or ritualistic behaviors. Compulsive behaviors may include touching or rubbing objects, checking repeatedly to see if doors are locked or if the stove is turned off, ripping, breaking or hitting objects, etc. In the most severe cases, self-mutilating symptoms may occur including head banging, biting, or hitting oneself. Examples of ritualistic behaviors may include compulsively walking through doorways with a specific foot first, jumping, hopping, touching the floor, having to arrange and rearrange objects in a specific manner, etc. These can be the most crippling behavioral symptoms of TS because they consume so much time.

Diagnosis

Many persons with TS are misdiagnosed for a lengthy period of time due to professional unfamiliarity with the syndrome. Commonly, families have brought children to a wide variety of professionals during their search for a diagnosis. Individuals may be told their symptoms are caused by psychological factors and will often be referred to mental health practitioners. They are often wrongly advised the symptoms are "nervous habits" which will disappear eventually, or they are misdiagnosed with a variety of ailments. As a result, some people with TS have been treated with ineffective and even dangerous therapies. The correct and/or confirming diagnosis and treatment plan should be made by a neurologist, psychiatrist, or neuropharmacologist familiar with diagnosis and treatment of Tourette Syndrome.

Treatments

The only proven effective treatments for Tourette Syndrome are pharmacological. Most often used medications include neuroleptics such as haloperidol (Haldol), pimozide (Orap), fluphenazine (Prolixin), clonidine (Catapres) which is an anti-hypertensive medication, and antidepressants for obsessive-compulsive symptoms such as clomipramine (Anafranil) and fluoxetine (Prozac). Information about each of these medications is available through the Tourette Syndrome Association. It's important to consider side effects of any therapeutic agent when dealing with a client who has TS. Some medications can cause severe depression, short-term memory problems, cognitive interferences, etc. Psychotherapy is not an effective treatment for the symptoms of TS. However, it can be very helpful in assisting TS clients to adjust to, understand, and cope with the effects of Tourette Syndrome. The need for assistance with this adjustment cannot be minimized.

Implications

The motor, vocal, and behavioral symptoms of TS can be quite disturbing to the person with TS, his or her family, and society in general. TS symptoms are often perceived as bizarre and frightening. The years during which a client is undiagnosed or misdiagnosed can have a lasting psychological impact. The client may have been punished by family, rejected by teachers, teased by peers and looked upon as a disruptive or emotionally disturbed child. Children with TS shouldn't be placed in time-out or in E/BD programs.

It isn't surprising that the undiagnosed person with TS often begins to question his or her own sanity. However, studies have shown that the severity of motor and vocal symptoms aren't the predictors of satisfactory or unsatisfactory adjustment. Rather, the behavioral disabilities, degree of family support, effectiveness of medication, educational level, intelligence, etc., can help or hinder a person's later independence and productivity. Some people with very severe motor and vocal symptoms have succeeded in all areas of life and even pursued professional careers which exceed the goals of people without disabilities. Others, with only minor motor and vocal symptoms, can be severely disabled by their behavioral symptoms and/or emotional maladjustment. There's no set formula which draws a line between the difficulties a person with TS faces in his lifetime as a result of having the disorder, the implications of misdiagnosis, and those behaviors which are a part of the syndrome itself. "Where does the Tourette Syndrome end and the person begin?", is a question often asked by service providers who are working with a person with TS. Like most neurological impairments, this answer is not yet clear.

Important Characteristics

People with TS can postpone or substitute symptoms for a variable period of time. Implications of this characteristic may be both positive and negative:

- People with TS tend to hold back their symptoms when in the presence of strangers. Thus, one reason TS is often misdiagnosed is because the person may not display symptoms in the doctor's office. It's important that the diagnosing physician schedule a lengthy initial office visit. If symptoms don't appear after some time, persons with TS should be asked to sit in a place where they're unaware of being observed (i.e., a waiting room). At that time the symptoms will probably be expressed.
- A great deal of energy and concentration must be used to hold symptoms back while they're being postponed. At those times, the client is usually not listening to speakers, teachers, etc., and performance can be impaired. In a learning situation, it's bet-

ter to allow symptoms to be expressed.

- Symptoms will be expressed more explosively after they've been held back. Therefore, persons with TS should be given a "safe place" to go where they may release their symptoms without disturbing others. In school this can be an empty classroom, nurse's office, etc. At a place of employment, a nearby restroom or an office providing privacy might be used.
- The great majority of people with TS can drive cars and work with various equipment. They don't lose consciousness during their tics. Since they can postpone or substitute symptoms for varying periods of time (according to the severity of the case), they are usually able to do precise work without their motor movements interfering. As soon as a task is finished, they may have to express more intense repetitive movements in order to compensate for the postponement of motor activity. Therefore, they may require extra time to complete a task.
- The compulsive component of TS can some times work to the person's advantage. Many people with TS feel that they must do things perfectly. As a result they can be excellent workers because they will settle for nothing less than a job well done. This characteristic, if it doesn't become too time consuming or ritualistic, can be one of the client's greatest assets.
- People with TS have the same range of intelligence characteristic of the general population. A few cases of mentally retarded people with TS have been reported, while the remainder have average to above-average intelligence.

Educational Implications

The educational implications of TS are complicated because of the variable degree of social factors, learning disabilities, cognitive impairments caused by medications (or occurring naturally), teacher unwillingness to accept TS symptoms, the degree of motor and vocal control, and the effects of psychological stress. Tourette Syndrome is a handicapping condition under Federal Law – the "Education for All Handicapped Children Act" (PL 94-142) now updated as IDEA. Children with this neurological impairment are eligible for special education and related services. Sixty percent of children with TS have identifiable learning disabilities which can intensify their difficulties in the classroom.

Learning disabilities associated with TS often involve mathematics and/or certain areas involving language. Sometimes math problems actually involve handwriting difficulties such as not writing numbers in the correct column, placing decimal points in the incorrect place, etc. Language difficulties can involve both the understanding of language and language production. These difficulties usually don't become apparent until the upper grades when the child is expected to comprehend more complicated vo-

cabulary and sentences.

The most common problem faced by students with TS involves their basic responsibility to sit still, pay attention and be quiet. Because they aren't always capable of doing this they must be allowed some freedom of movement and not be reprimanded for being fidgety, taking too many trips to the lavatory, etc. Attention Deficit Disorder (ADD) is a common component of TS, and the student may often need to be guided back to the task by teachers.

Another common problem involves handwriting difficulties. Handwriting may be sloppy or illegible. People with TS may have great difficulty forming letters, they may compulsively tear paper, put dots in places where they don't belong, or go over and over letters. In those cases where handwriting doesn't appear to be sloppy, we often hear that the "perfectionist" compulsive behaviors which make the child write neatly (and if it's not neat enough, the child will do it over and over again) take extensive periods of time. Children with TS generally find it difficult to copy notes from a blackboard and may require hand written notes on a piece of paper so that they don't have to focus from a near to far distance repeatedly.

The writing problem is also impacted by the psychological effects of stress. Stress always makes tics worse, and time limits are a common source of stress to students with TS. In these cases tests should be given without time limits, and sometimes in a separate quiet room. At times substitutes for writing must be offered; the child can be given a tape recorder or allowed to dictate answers to another person; written notes can be given to the student by a classmate who has used carbon paper while taking notes.

Behaviors can also cause educational problems. The child may be perceived as hyperactive and/or a discipline problem because he or she disturbs peers, calls out in class, touches other people, etc. These behaviors do indeed represent a problem for a classroom teacher. However, proper diagnosis, medication (when indicated), appropriate adjustment to the child's program and/or psychotherapy might be appropriate interventions according to the individual circumstances.

Adapted from materials prepared by the Department of Family & Professional Services, Tourette Syndrome Association, Bayside, NY.

Why This Information is Important for the Health Paraprofessional

The health paraprofessional needs to be aware of these symptoms and may be called upon to help in the classroom or on the job with the individual or offer a quiet place for the individual to go to when needed. Most often with the individual with TS, the paraprofessional may also be delegated to dispense prescribed medications during the day.

Section 19

Tuberculosis

Tuberculosis (TB) is a contagious disease that primarily affects the lungs. Until recently, tuberculosis had become a nearly forgotten disease in the United States. Once treated in remote fresh air sanitariums, the public no longer considered this contagious disease a significant threat to their health. Improvements in drug therapy, nutrition, hygiene, and hospital care in the 1950s had kept TB in steady decline until 1986. Today, an estimated ten to fifteen million Americans are infected with TB and over 20,000 new cases are reported annually. The most notable increases in infection rates have occurred in groups and in areas with a high prevalence of AIDS or HIV infection. According to the Center for Disease Control (CDC), the incidence of TB in persons with HIV infection is almost 500 times greater than in general. Additionally, new drug-resistant strains of the disease have recently been reported.

There are two very frightening facts about TB. First, anyone can get it: nothing more than breathing is required for transmission to occur. Second, despite the fact that TB is preventable, easily detected, and is today a largely curable disease, five percent of all cases are first reported at death.

Transmission

TB is spread by airborne bacteria produced by a person with untreated TB of the lungs or larynx when she or he coughs, sneezes, speaks, or sings. Another person who repeatedly inhales air contaminated with the bacteria may become infected. Persons at highest risk of being infected are close contacts, such as those living or working with an infectious person. The duration of exposure required to transmit TB is highly variable and depends on the infectiousness of the source case. Many studies seem to indicate that TB is more infectious in persons with HIV.

Inhaled particles containing the TB bacteria are usually trapped in the protective lining of the respiratory tract and are expelled. When this happens, no infection occurs. However, tiny particles may be inhaled beyond the clearance mechanisms and may be carried to the air sacs of the lungs where they can establish an infection. In most persons with a healthy immune system, the infection is contained and active tuberculosis doesn't develop. Even so, a healthy immune system often doesn't destroy all of the bacteria and small numbers of dormant organisms remain in the body. Some infection may be carried by the lymph system or the bloodstream to distant tissues and organs. With dormant organisms in the body, a person remains at risk of developing active TB. Unless preventive measures are taken to eliminate these dormant

organisms, the germs may overcome the body's defenses at any time and begin to multiply; active disease will then develop.

Although the lung is the most common site, TB may also affect other tissues or organs in the body such as the lymph system, the gastrointestinal system, the brain, or the joints. Only persons with pulmonary TB (TB of the lungs or larynx) are contagious to others: because TB is spread by airborne droplets, TB contained in other tissue or organs is not contagious.

TB Infection vs. TB Disease

TB infection is not the same as TB disease. A person infected with TB has the potential to develop the disease at any time but doesn't have the disease. TB infection is diagnosed by a skin test while TB disease is diagnosed by evidence of organ damage and cultures (tests that show the organism).

Persons who are infected but don't have clinically active pulmonary TB are not infectious. Once infected, a healthy person will give a positive reaction to a skin test that gauges whether or not their immune system recognizes the protein from the TB bacterium. This is known as an *asymptomatic primary TB infection* because the infection is associated with a positive skin test but occurs in the absence of signs of the disease.

Unfortunately, the symptoms of TB disease are vague and vary with the location of the infection. Symptoms of pulmonary TB include a moist cough lasting more than three weeks, chest pain, or coughing up blood. Symptoms typical of active TB anywhere in the body include fevers, chills, weight loss, loss of appetite, fatigue, nausea, night sweats, and weakness. If symptoms are present despite a negative skin test, further diagnostic studies should be done to rule out TB. As TB is a slow growing organism, bacterial cultures may take as long as twelve weeks to grow, although a bacterial smear may give earlier information as to the type of bacteria present.

Diagnosis

The Mantoux TB skin test (purified protein derivative or PPD) is recommended for accurate diagnosis. This test involves using a small needle to inject tiny amounts of purified tuberculin protein into the upper layers of the skin, usually on the inside of the forearm. The skin test gauges the immune system's familiarity with TB. If the immune system recognizes the skin test protein as one it has dealt with before, the injection site will become reddened and swollen (indurated). The test is read in 48-72 hours by measuring the size of the induration.

Because of damaged immune systems, HIV infected persons may not be able to generate the immune response necessary to react to a TB skin test. A smaller amount of induration is then in-

terpreted as a positive skin test in persons who are HIV positive. A positive skin test indicates that an individual has been exposed and is infected. Further diagnostic studies are required to diagnose TB disease.

Many HIV infected persons may not be able to react to the tuberculin protein at all because of damage done to their immune system by HIV. This is known as *anergy*. Anergy testing, done to determine whether or not an immune response can be generated, should be performed along with the Mantoux TB skin test.

Anergy testing involves the injection of tiny amounts of proteins to which most people have been exposed, usually mumps, candida or tetanus toxoid, into the upper layers of the skin and watching for a response. If a person doesn't respond to these very common proteins, it's likely that he or she would also not be able to respond to the TB protein. A negative TB skin test along with a negative anergy test, then, doesn't assure us the person is free of TB infection.

Treatment

Early diagnosis and treatment is the key to limiting the spread of TB. In most cases, appropriate antibiotic therapy quickly eliminates a large number of infectious organisms and after a few weeks of treatment a person is no longer infectious. Most persons infected with TB should receive preventive drug therapy so that they don't go on to develop TB disease. The risk of an otherwise healthy infected person with TB infection developing active TB is about ten percent during their life time. Nine of ten persons would not ever develop TB even without preventive therapy.

The goal of preventive therapy is to prevent TB infection from developing into active TB. Current preventive therapy involves six to twelve months of Isoniazid taken daily. The CDC currently recommends a twelve month course for HIV positive persons. Twelve months of therapy will reduce the risk of tuberculosis by over ninety percent.

Some clinicians recommend preventive therapy in anergic HIV infected persons who are at risk of contracting TB. Standard antituberculous drugs are not, however, without risks. Ten to twenty percent of patients receiving standard therapy develop liver toxicity. As most men with hemophilia already have some degree of liver disease, the benefits of prophylactic therapy must be carefully weighed.

There are a variety of drugs available for treatment of TB disease. Treatment should involve the use of at least two – preferably three – drugs in combination to help prevent the emergence of resistant organisms.

The goal of all treatment is to provide the most effective therapy in the shortest time; however, adequate treatment of TB involves long-term drug therapy. While most persons with hemo-

philia have grown to accept long-term drug therapy as a necessary part of life, many others have not. It's often very difficult for people to take medications on a long-term basis, especially when they're feeling well. Antituberculous drugs eliminate most susceptible germs quickly and relieve bothersome symptoms, but the strong, obstinate organisms that may remain can mutate and become resistant to standard TB therapy. Should these remaining resistant organisms again become active, the resulting disease will be more difficult to treat and the infected person will be capable of transmitting the drug-resistant disease.

As previously noted, strains of TB that are resistant to many antituberculous drugs have been reported around the world. In the United States, approximately seven to ten percent of reported cases involve drug-resistant organisms. Primary resistance occurs when a person is infected with an organism that is already resistant. Secondary resistance occurs when the organisms become resistant during the course of therapy. The occurrence of primary antituberculous drug resistance is an indicator of transmission of a resistant organism from patients who have received inadequate or inappropriate treatment.

Treatment of drug-resistant TB is very difficult. Additional drugs are usually added to the standard regimen in hopes that the organisms will not be resistant to them. Recently, strains of TB bacteria have been isolated which are resistant to all of the first-line, most effective drugs and successful treatment has been very difficult.

Information taken from the Hemophilia Update, First Quarter, 1993, Number 30, Hemophilia Foundation of Michigan, a United Way Agency.

Why This Information is Important for the Health Paraprofessional

Because TB is on the rise – and many people aren't aware that it is – they may not detect the symptoms in an individual they work with. You must know these symptoms so you can, if needed, refer an individual for further help and treatment. By being able to describe these symptoms to others who may work with students in the classroom, you may help them in discovering TB early and helping the individual in the early stages of infection.

Summary

Individuals may have any number of many disabilities. The disabilities included in this chapter were identified by LSNs as those they see most frequently in the school setting. It's important for SHPs to be aware of basic information about disabilities so they

will be familiar with these conditions. Understanding a specific disability can provide the SHP with greater empathy and greater awareness to meet as individual's needs.

Questions to Ponder

- When working with any person with a disability, what are common issues the individual must face?
- What's your role in working with individuals with disabilities?
- How can you assist individuals with disabilities to meet their basic needs?

9

Chapter Nine

Selected Health Procedures: Specific Instructions

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Introduction

This chapter is designed to give health paraprofessionals some specific direction in terms of selected health care they may be asked by the LSN to perform on the job on a regular basis. The following areas have been chosen because they are the most common situations found by health paraprofessionals.

Many of the sections in this chapter are broken into four parts: *Definition, Equipment Needed, Student Considerations and Accommodations, and What to Ask*. The sub-sections are designed to give you the information in as simple and as useful a manner as possible.

This chapter discusses some selected health procedures from a general description only. These are conditions aren't described in detail because, while you might be exposed to them, you must first have specific training beyond the scope of this module to work closely with each of these conditions. The LSN will usually provide the SHP with specific training, demonstrations, and supervision.

Section 1

Assisted Eating

You may be working in a setting where individuals need help eating. There may be classroom paraprofessionals who handles most of this support or you may also be called upon to offer assistance.

Many individuals who need assistance eating will have specially designed or adapted equipment for this purpose. This equipment is usually designed or modified by an occupational therapist. Such equipment may include a spoon adapter or a spoon bent in such a way as to assist a particular individual's needs. Adaptations may also be a plate with built-up sides or a plate or bowl with a slip-proof bottom. Other adaptations may be more specialized.

The following are some tips to remember when assisting someone with a disability with eating:

- Make sure the student is seated properly – sitting up straight with feet on the floor.
- Sit at the student's eye level.
- Be careful to use the correct adapted equipment with the right student. Because it's specially designed for each person, you must make sure you have that person's equipment. All the dishes and adapted equipment are often kept together on a tray. Make sure it's marked or there's a chart so everyone knows what equipment belongs to whom.
- Be careful to give each individual the correct food and be careful not to feed the individual too much, or too much at one time.

Discussion

Discuss these procedures. Ask students for questions and input. Give examples of situations where paraprofessionals may be asked to perform these procedures.

Discussion 1

Students will read these tips about assisting an individual with eating. Discuss the tips and ask students to draw on their experience for any additional ones that would be helpful.

- Offer the food separately rather than mixed together. Alternate types of food.
- Watch for individuals who may be “packing” food in their mouths but not really chewing and swallowing it. If the individual is packing food or ruminating, or chewing for a long time although you continue to give him or her food, there’s a danger he or she might choke. Watch carefully.
- Students who have difficulty in swallowing need to have food cut into small pieces or foods with thicker consistencies (easier to swallow). The SHP should stay nearby to observe eating and needs to know proper first aid for choking.
- Give the individual the amount of time he or she needs to eat, but set a limit on the amount of time.
- Encourage the student to help him- or herself as much as possible.
- Provide a pleasant environment for the individual while eating. Play music, eat with the mainstream population, talk with the individual.
- Encourage the supervising teacher or licensed school nurse to keep a laminated index card containing current on each individual posted in a designated area. This card should list the adapted equipment the person needs for eating, dietary requirements, food allergies, and any other special instructions that people providing assistance in eating need to know about each student.

Section 2

Body Mechanics & Handling/Positioning

Discussion 1

Many of the sections in this chapter focus on individuals who may require assistance in mobility or in positioning themselves (for activities such as toileting). It’s important for students as paraprofessionals to understand not only assistive devices but also proper – and *safer* – ways of assisting and lifting. Read these sections and the principles of body mechanics found in Appendix M, and discuss them as a group.

Walkers, wheelchairs, crutches, canes – all of these devices have one purpose: to aid mobility. This is a major concern for many individuals with a chronic health condition or disability that impairs mobility. A person’s ability to move from one location to another is obviously crucial, not only for learning but for feeling “a part of the group.” You may be called on to help.

This raises a whole series of questions: What is the best way to transfer a person from a wheelchair to another surface, such as a chair or toilet? What individuals are good candidates for power wheelchairs? A person with no mobility may need lifting to be placed on a toilet seat; how do we do that without injuring the individual – or caregiver? How can we put the individual in a sitting or standing position so he or she can take part in the activity?

Individuals with physical limitations vary widely in mobility.

Some are totally dependent. These individuals, for example, may use a wheelchair; you would have to lift them when transferring them from a wheelchair to a toilet. In contrast, other individuals will never use a wheelchair. They will walk and transfer themselves independently, perhaps with the aid of an orthosis, a supportive device, or both. (Orthoses are appliances that provide support to a limb or joint).

You may become directly involved with an individual's transfers and any equipment needed for that purpose. Before you do, gather information about:

- Medical diagnosis, including special problems such as susceptibility to fractures.
- Equipment currently being used, such as wheelchairs, orthoses or walkers.
- General level of mobility.
- Any recent surgery that may affect handling techniques.

Levels of Mobility

Level I: Totally Dependent

Individuals at Level I may have voluntary head control, but require support to sit. They need to be totally lifted for transfers and are dependent for all care. Examples are individuals severely involved with cerebral palsy, individuals with a high level myelomeningocele (spina bifida) or spinal cord injury, or those in the advanced stages of Duchene's muscular dystrophy.

Your goal at this level is to safely transfer the individual and to promote self-care. Many individuals who need total lifting are severely spastic. For example, individual with cerebral palsy tend to hold their bodies in a totally extended position. In order to place them in the sitting position, it's best to bend them sharply at the hips. Hold them in this flexed position as you place their buttocks down and back and then secure any lap belt.

Safety Precautions: Because these individuals require extensive lifting, the greatest safety concern is that the caregivers not harm their backs by lifting too much weight. If you have any doubt, get help before starting to lift. Always have two people present if you're transferring an individual for the first time.

Making a Transfer: These are the steps you should take to safely transfer an individual at Level I.

- 1 Plan the transfer carefully. Place the individual as close as possible to the surface to be occupied. Make sure there are no obstacles and that the surface is stable.
- 2 Lock any wheels on the chair or buggy in which the individual is sitting. Do the same to any chair or buggy in which you're

placing the individual.

- 3 Unfasten any straps or buckles.
- 4 Bend your knees and keep Your back as straight as possible. Do the majority of the lifting with your legs, not your back.
- 5 Reach behind the individual at the shoulders and under the buttocks. Support the head and legs with your arms.
- 6 Keep the individual as close to your body as possible. Lift and come to a full standing position.
- 7 Move to the new surface and lower the individual by bending your knees. Keep attending to the individual until the straps have been secured.
- 8 Coordinate the moves of the people lifting with verbal cues.

A two-person transfer may be needed for lifting a larger individual, and the procedure is similar. There's a difference, however: one person lifts under the shoulders and low back. The second person lifts under the buttocks and knees.

Level II: The Individual in a Wheelchair Who Assists with Some Mobility

An individual in this category would be seated in a wheelchair most of the time. This individual, though probably unable to propel a manual wheelchair, could manage a powered chair. He or she could assist with self-feeding and dressing. Examples would be individuals with mild cerebral palsy or muscular dystrophy less advanced than Level I.

Your goal at this level is to safely transfer and assist the dependent individual, allowing him or her to help as much as possible.

Safety Precautions: This individual provides minimal help in transferring. Still, proper lifting techniques are essential to help caregivers avoid back strain. If you have any question about this, get more help before starting to lift.

Making a Transfer: These are the steps you should take to safely transfer an individual at Level II.

- 1 Plan carefully to minimize the distance the individual must be moved. It's best to move from one surface to another without taking any steps.
- 2 If possible. Ask the individual to do a standing pivot transfer. Start by locking the wheelchair in such a position that a quarter-turn will get the individual from one surface to the other. This works best when the individual is able to bear a little weight on his or her legs, and is not obese or excessively tall.
- 3 Unfasten any straps or buckles: face the individual. Put a transfer belt on him or her if necessary. Help the individual to slide

forward as much as possible.

- 4 Ask the individual to put his or her arms around your neck, if possible. Grip the safety belt behind the individual, or get the individual's buttocks. Bend at your knees, not your waist.
- 5 Agree on a pre-arranged signal. At the signal, the individual should try to stand as you lift by straightening your knees. When the individual is in full stance, he or she can be supported by leaning against your body. Come to a full stand before beginning to turn.
- 6 Pivot together. Help move the individual's feet with your own if necessary.
- 7 Slowly lower the individual onto the surface by bending your knees.
- 8 Adjust the individual's position in the new location, making sure that buttocks are well back. Attach any buckles or straps.

Level III: The Individual Who is Independent in Wheelchair Mobility

Individuals at this level are mobile in the community in a wheelchair. They can accomplish transfers essentially without assistance and are independent in feeding and dressing. Examples are the individual who has cerebral palsy that only minimally affects the arms and hands, or the person who is paraplegic from a spinal cord injury.

Your goal at this level is to monitor the progress of the individual in mobility and transfers. To help plan for any further steps in independence, stay aware of changes in the person's skill level.

Safety Precautions: Be aware of the individual's limitations to eliminate any possibility of injury.

Making a Transfer: These are the steps you should take to safely transfer a individual at Level III.

- 1 Accompany the individual to all places he or she would regularly go. Make sure that these facilities are accessible.
- 2 Observe the individual doing transfers and assess their safety.
- 3 Be aware of individual's speed and endurance. That way you can provide help for difficult terrain or long distances, if needed.
- 4 If possible. Ask the individual to do sliding transfers, side-to-side with the new surface to be occupied. These transfers can be done at an angle or by having the individual turn completely around. A sliding board may help. As an alternative, ask the individual to independently do a standing pivot transfer with grab bars. If you think complete independence is a possibility for the individual - even though it hasn't been achieved

yet – ask for consultation from therapists.

- 5 Make sure grab bars are accessible. This is essential when the individual is able to take a few steps – for example, from wheelchair to bathroom.
- 6 Check the condition of the wheelchair frequently. The individual's position in the wheelchair and mechanical maintenance of the wheelchair are significant for the individual at Level III. When needed, recommend changes or repairs.

Level IV: The Household Ambulator

Individuals at Level IV can move about home, school, and work on their own power, using some combination of prescribed assistive devices. These individuals might require extra time to get from place to place, but they need no help or supervision with toileting. When going long distances or on rough terrain, these individuals can use a wheelchair and self-propel it.

Such individuals would most likely have mild or moderate cerebral palsy. However, they might also have lumbar myelomeningocele (spina bifida) or one of the low incidence disabilities, such as dwarfism.

Your goal at this level is to monitor the safety and accessibility needs of an individual who primarily walks around.

Safety Precautions: Be aware of the individual's limitations to eliminate any possibility of injury.

Making a Transfer: These are the steps you should take to safely transfer an individual at Level IV.

- 1 Accompany the individual to all places he or she would regularly go. Make sure that all facilities are accessible.
- 2 Observe the individual in all areas to assess safety – especially on stairways and terrain that must be covered in bad weather.
- 3 Be aware of circumstances requiring the individual's speed or endurance. Determine whether or not the wheelchair is appropriate in such circumstances.
- 4 If the individual uses a walker. Make sure it provides the most support available. When using the walker, the individual should put it forward less than arm's length, then take a step with each foot. After stepping, the individual's body should still not be in contact with the front cross bar.
 - **Test for ideal walker height:** Ask the individual to stand erect, in line with the rear legs of the walker. The individual's elbows should be flexed about 30 degrees with hands on grips.
- 5 If the individual uses axillary crutches, make sure he or she uses proper technique. The individual can advance crutches simultaneously and then take a step with each foot or hop for-

ward. An alternate way is to advance one crutch and then step with the opposite foot.

- **Test for ideal crutch height:** A crutch is at an ideal height when the individual, standing erect, has two finger-breadths between armpit and top of crutch pad. The legs of the crutches should be several inches forward and to the side of toes. Elbows should be flexed about 30 degrees with hands on grips.
- 6 If the individual uses four-point canes, forearm crutches, or any other assistive devices. Make sure he or she uses the proper technique. The walking patterns can be similar to those above.
- 7 For some individuals, consider a less supportive device. This issue comes up when an individual is using an assistive device and appears to be totally safe and efficient, or uses it only partially. Individuals are never ready for a less supportive device until they are skilled with the one that offers more support for balance. The most support is provided by parallel bars. Next comes the walker, axillary crutches, forearm crutches, four-point canes and single point canes. Axillary crutches are most commonly used by persons with a cast or broken leg; they aren't usually meant for long-term use.
- 8 Make the change to a new assistive device in consultation with the individual's medical facility or a physical therapist. Direct treatment in therapy may be needed to make the transition.

Level V: The Community Ambulator

Individuals at Level V never use a wheelchair. They participate fully in all age-appropriate social activities. These individuals may use lower extremity orthoses or assistive devices. They need no help for self-care activities. However, they may need to make some adaptations to participate in sports. Examples of individuals at this level are those with mild cerebral palsy or with one or more limbs missing.

Your goal at Level V is to monitor the individual's progress in mobility. Keep track of changes in equipment or adaptations needed for mobility, sports or recreation.

Safety Precautions: Be aware of the environmental hazards such as uneven floors, dark corridors, loose stair treads, etc. These may interfere with safe mobility. Prevent disrepair or breakdown in assistive devices or orthoses.

Making a Transfer: These are the steps you should take to safely transfer an individual at Level V.

- 1 Accompany the individual to all places he or she would ordinarily go. Make sure that all facilities are accessible.
- 2 Observe the individual in all areas to assess safety – particularly on stairs, rough terrain and in crowded places.

- 3 Be aware of circumstances requiring speed or endurance from the individual. This helps determine if the individual needs to start early or be allowed to arrive late.
- 4 Be aware of changes in the individual's status – such as use of a walker, cane or other device – that may call for different accommodations.

Adapted from *Managing the Student with a Chronic Health Condition: a Practical Guide for School Personnel*, developed by Pathfinder and the School Nurse Organization of Minnesota, 1986.

Handling and Positioning

Handling refers to how an individual with a disability who needs to be moved is handled. There are specific ways that this should be done to both ensure the safety of the individual and the health of the one doing the moving. *Positioning* refers to how a person is put in position (a part of handling) to ensure his or her comfort and access to what is needed.

Equipment Needed

- Transfer belt (depending on the needs of the individuals)

Student Considerations and Accommodations

- Proper physical handling and positioning of individuals with disabilities who need assistance is basic care. Handling activities include lifting, carrying and transferring of individuals.

The use of correct handling techniques minimizes the risk of injury to students and to staff in performing these potentially physically stressful tasks.

Proper positioning ensures that individuals will be able to participate in activities as actively and comfortably as possible. Certain positions enable individuals to have better control of their body parts (e.g., head, arms, etc.). The goal of proper positioning is to provide adequate support and postural security (balance) for function and to prevent the development of abnormal motor patterns that can cause physical deformities. In addition to correct positioning, range of motion and relaxation exercises done on a consistent basis facilitates the individual's mobility and functioning in activities. Because teachers and assistants have primary responsibility for individuals during the school day, it's important that they be well-trained to handle, position and carry out needed exercises with correctly.

- Daily activities that require training for program assistants with respect to proper handling include the following:
 - Assisting students in getting on and off of school vehicles at arrival and dismissal times;

- Facilitating student mobility to and from the classroom and other school or community-based locations during the day;
- Positioning students for instructional activities with the aid of adaptive equipment;
- Physical handling involved in oral motor practice and feeding activities (breakfast, lunch, snacks);
- Toileting requiring the transfer of students to and from wheelchairs or other adaptive equipment;
- Carrying out required range of motion and relaxation exercises with individual students.
- As a part of handling and positioning, your goals and considerations with the student should include:
 - Obtaining greatest degree of motor skill possible
 - Facilitating as much active participation from the student as possible
 - Facilitating quality, active movement
- As part of the handling and positioning process, your goals for yourself should include:
 - Normalizing muscle tone before demanding active control;
 - Learning by feeling desired movement;
 - Having stable base from which active movement can occur;
 - Breaking up total body responses and develop isolated active control of specific body parts.

What to Ask

- If the individual is unable to tell you what position is best for a given situation, ask those who will know (parents, family, etc.) *Don't* assume you know what's best.
- Remember to make sure the individual is included in activities. Don't allow him or her to be excluded because he or she is out of the range of vision or hearing because someone forgot to reposition the individual. Ask ahead about the plans for the group so the individual can be positioned appropriately.
- Find out what the location options are for meals. Ask the individual (or family) what location will work best for them.

Section 3

Bowel Care

Bowel care includes promoting the student's usual pattern of bowel functioning. This may involve following the plan established by the student's parents and/or caregiver, physician, or other health care professional in the community. Staff may be involved in initiating a plan to promote adequate and regular bowel func-

Discussion 1

Discuss definitions, equipment needed – making additions to the list if necessary – individual considerations, and what to ask the individual. Students will add to these sections as appropriate from their experience.

tioning. Factors that contribute to optimal functioning include a high-fiber diet, adequate fluid intake, scheduling for elimination at regular times each day, possible planning for toilet training, providing a conducive environment, proper positioning for elimination, and physical activity or exercise.

Equipment Needed

- An adapted toilet chair
- A special toilet chair constructed to sit over the toilet
- A stool for the individual's feet may be used
- A support bar for the individual to grasp

Student Considerations and Accommodations

- If an individual has trouble chewing and swallowing, and needs an increase in fiber content in his or her diet, this may be difficult. The individual may need to eat blended, pureed, or baby foods, but commercial baby foods contain very little fiber, so table foods can be placed in a baby food grinder or food processor to obtain the best texture for the individual with oral-motor impairment. One can also mix unprocessed bran in food each day to supply additional fiber.
- Individuals need one to two quarts of fluid a day. This fluid should consist of as little sweetened or carbonated beverages as possible. Prune juice has a natural laxative effect and can be combined with another fruit juice to taste more appealing.
- In an effort to develop a schedule of elimination with the individual, Some strategies for promoting the individual's normal schedule of elimination include placement of the individual on the toilet after meals and snacks to take advantage of the gas trocolic reflex that usually occurs after meals. Whatever pattern is established at school should be communicated to and agreed upon with the family. The goal is to provide as much consistency for toileting patterns throughout the individual's day and week as possible. The method used for toilet training must be appropriate and individualized for the individual, with the individual's family and school staff working with him or her.
- If the individual doesn't have control over elimination of feces, staff will need to check the individual's underclothes or incontinent wear often. Determine with the individual and the family how this can best be done. Also ask the individual and the family about the condition of his or her skin. If skin is very sensitive, staff may need to check more often to avoid sores.
- To facilitate defecation, make sure to position the student carefully and offer a conducive environment (you may need to ask

the individual or family what works best for the individual). The individual may have special techniques that may facilitate defecation, such as leaning over in order to push down by blowing up a balloon, blowing bubbles, coughing, or pressing on the abdomen. Digital stimulation of the rectum may be needed to initiate defecation. This procedure should be done only with the guidance of qualified health personnel.

- Proper positioning on the toilet seat may facilitate defecation. A squatting position best facilitates defecation. When an individual cannot sit up alone or assume a position similar to squatting, his or her head and trunk can be elevated with the hips flexed at 90°. An adapted toilet chair may be needed if the student has difficulty with balance or trunk control. The paraprofessional who helps in these activities must be sure to carry out thorough hand washing afterward to prevent bacteria from spreading to other individuals or school staff. Hand washing after assisting with toileting must be carried out in a sink that is not used for food preparation.
- The physical therapist or physician may have developed an exercise program to help the individual be able to eliminate more regularly.
- There are two warning signs that may indicate problems for the individual: diarrhea and constipation.

Diarrhea is defined as watery, copious bowel movements that are usually green in color and have a foul odor. Characteristics of diarrhea include a noticeable or sudden increase in the number of stools; change in consistency with an increase in water content; and a tendency for stools to be greenish in color. Diarrhea may also be caused by diet, medications, milk allergy, food poisoning, parasitic infections, obstruction of the intestine by a large mass of hard stool, or other illnesses. When determining whether the student has diarrhea, consider the number and size of stools in a twenty-four-hour period; the consistency and color of stools; and the presence of other signs such as fever, irritability, cold, cough, lethargy, decreased appetite, vomiting, and abdominal pain. The family should be notified. One of the major concerns with diarrhea is the risk for developing dehydration.

Constipation is the retention of feces in the intestinal tract or a delay in excretion of feces from the rectum. Constipation exists when the interval between bowel movements is greater than the time normal for the individual, when the volume is small and feces remain in the rectum, and when the consistency of feces is hard and dry. Constipation is generally restricted to situations in which an individual has fewer than three bowel movements per week. A change in the frequency of stools is more significant than the frequency itself. In addition to the change in frequency, size, and consistency of stools,

other signs of possible constipation are abdominal pain, enlargement of the abdomen, nausea, decreased appetite, no appetite, or painful defecation.

Constipation is often caused by a low fiber diet, inadequate fluid intake, dehydration, malnutrition, voluntary withholding of feces, defective innervation of muscles as in spina bifida and paraplegia, decreased muscle tone as in Down syndrome and cerebral palsy, and side effect of certain medications. Increasing fiber in the diet often aids in relieving constipation, as does increasing the intake of fluids; promoting a normal bowel pattern; minimizing the number of distractions while toileting; positioning properly on the toilet seat; ensuring that physical activity occurs as allowed; and using suppositories, laxatives, or enemas (only if prescribed by a physician, nurse practitioner, or clinical nursing specialist).

What to Ask

As a paraprofessional working in the health office you may be called upon to help with toileting, bowel movements or related concerns frequently. It's important for you to know the warning signs of constipation and diarrhea so you can ask the individual and staff members for symptoms of possible problems. Always ask the individual, when helping him or her with toileting or what is needed from you and be as accommodating to his or her needs as possible. Treat the person carefully, respectfully, and discretely.

Section 4

Cast Care

Discussion 1

Go through each section of cast care with students and ask them to add to the information here based on your discussions.

Cast care means helping an individual who has a cast on a body part to keep it in good condition, and prevent additional problems to the individual's body while wearing the cast. Four major requirements are included in cast care: protecting and cleaning the cast; assisting the student with a cast in toileting activities (if necessary); checking the condition of the skin around and underneath the cast; and checking for the continued correct positioning of the cast.

Equipment Needed

- Cleaning the cast requires a mild abrasive cleanser and water.
- Plastic wrap to keep those areas that are susceptible to soiling clean.
- A flashlight is needed for determining whether the area underneath the cast is free of foreign objects.

- For individuals in a hip cast, a bed pan and urinal (for males) are required instead of the usual toileting facilities.
- Alcohol is used on the skin surrounding the edges of the cast to reduce the likelihood of the skin being injured.

Student Considerations and Accommodations

- Maintain cast care with the individual so he or she can participate in as many activities as possible.
- Daily cast care involves care of the new cast, preventing cast soiling, bathing the individual with a cast, managing the activity of the individual with a cast to prevent any harm or injury to the individual as a result of wearing the cast, and monitoring the fit of the cast.
- Monitor the individual's behavior closely with a new cast for the first seventy-two hours so he or she doesn't "dent" the cast. This would cause pressure under the cast.
- Monitor the individual so he or she doesn't get the cast dirty. This can be done by covering the cast (like during meals) with a plastic bag. If the cast becomes dirty, it can be cleaned with any mild abrasive cleanser and a slightly damp cloth. The cleansing powder is rubbed into the cast to remove the soil, lightly rinsed, and the cast is allowed to dry.
- If you're involved in bathing an individual in a cast, remember first, the cast must remain dry. A sponge bath is the best alternative to preventing the cast from getting wet.
- Monitor the individual's activity. Tell him or her to watch for food falling into the cast, or moisture around the cast. If an individual cannot verbalize discomfort at certain points on the cast, watch his or her behavior to see if you notice some kind of change that could indicate sore skin, etc.
- Checking the student's circulation includes checking the fingers or toes of the casted limb for color, proper temperature, presence of any swelling, and capillary filling. If all is well, the fingers or toes will be pink in color and warm to the touch. There will be no swelling in comparison with those on the other limb.
- Check the sensation to touch and movement routinely to evaluate determine the fit of the cast. The sensation and movement can be examined by touching the toes, fingers, and so forth. If the individual moves or wiggles the toe or fingers when they are touched, sensation is present.

What to Ask

- Ask the individual if he or she is having pain or discomfort from the cast. If there's more pain than is expected, the family

should be notified.

- Ask the individual if there's any problem with the cast, such as wetness or something falling into the open ends.
- When the individual first gets the cast, help him or her adjust to position and help make any necessary modifications or accommodations in the environment.

Section 5

Diapering

Discussion 1

It's very important to emphasize these points when training individuals to perform diapering procedures for individuals with disabilities. Go through the following procedures and then discuss them as a group. You may want to demonstrate some of the procedures for clarification. Explain the differences in diapering individuals based on their age or disabling condition. Refer students to the diapering procedures listed in Appendix N.

Changing diapers in a sanitary manner is an important way providers can prevent the spread of infectious organisms. Germs found in the stool can be spread by the hands of staff or individuals, or through contaminated food, water, objects, or surfaces. Many diseases can be spread by contact with stool. These include infections caused by bacteria (*Salmonella*, *Shigella*, *Campylobacter*, etc.), parasites (*Giardia*, pinworms, etc.), and viruses (rotavirus, Norwalk virus, and hepatitis A). You can help prevent illness by following the diapering guidelines described below.

Basic Principles

- Change diapers only in a designated diapering area.
- Separate diapering area from the food storage, preparation, and eating areas.
- Dispose of soiled diapers properly.
- Wash hands (staff and individual) after diapering.

Equipment Needed

Changing Surface

- Keep the changing surface away from other individuals, and preferably three feet from the floor.
- The surface should be a smooth, moisture-resistant, easily cleanable material.
- For extra protection, use non-absorbent, disposable paper (computer or roll paper) under the individual.

Hand washing Sink and Supplies

- The best hand washing sink is one equipped with both hot and cold running water mixed through one faucet (hot water temperature not greater than 120° F).
- Water controls ideally should be foot, knee, or operated to avoid contamination of hands.

- The sink should be next to the changing surface and separate from the food preparation sink.
- Keep liquid soap, paper towels, and fingernail brush within reach.
- Use single-use, disposable paper towels instead of cloth towels.
- Turn off faucet handles with wrist or a disposable paper towel.

Diapers

- High-absorbency disposable paper diapers are preferred because cloth diapers leak more and require more handling (the more handling, the greater chance of infection).
- All diapers must have an absorbent inner lining completely contained within an outer covering made of waterproof material that prevents the escape of feces and urine.
- For cloth diapers, the outer covering and inner lining must be changed together at the same time. Outer coverings must not be reused unless they are laundered.
- Ask your health consultant for approved procedures for the use of cloth diapers, if used.

Disposable Gloves

- Gloves should be worn when changing the diaper of an individual with diarrhea or a known infection that is spread through the stool.
- Pregnant women or women considering pregnancy may want to wear gloves when changing any diaper.
- Gloves should be worn by staff if they have open cuts, sores, or cracked skin, or if the individual has open areas on the skin.
- Discard gloves and wash hands after each diaper change.

Disposable Wipes

- Pre-moistened wipes must be dispensed in a manner that prevents contamination of the wipes or the container.
- If this is not possible, each individual should have a separate container of wipes, labeled with his or her name, and only used for that individual.

Skin-care Items

If skin-care items are used, keep them within the provider's reach, and out of the reach of children. Each individual must have his or her own labeled container of skin care products. Parents or the individual must provide written and signed directions and permission to use these products. Use skin-care items according to package directions.

- **Plastic bags:** Use disposable plastic bags to line waste containers and to send soiled clothing or cloth diapers home. Store

plastic bags out of any children's reach.

- **Waste container:** Use a tightly-covered container with a foot-operated lid. Keep the container away from individuals. Line the container with a disposable plastic trash bag. Empty container before full and at least daily, and clean it with detergent and disinfectant daily.
- **Toilet-training chairs:** Flush toilets are recommended rather than toilet-training chairs. If used, chair frames should be smooth and easy to clean. If toilet-training chair are used they must be emptied, cleaned with detergent and water, and disinfected after each use.
- **Cleaning supplies:** Use disposable gloves and towels, cleaning solution (detergent) and disinfecting solution (bleach).

Prepared by Hennepin County Community Health Department with support of epidemiologists and child care consultants from the Minneapolis/St. Paul area state and local health departments, March 1993.

Steps to Follow When Diapering

It's possible to spread infection when changing diapers, so perform the procedure carefully. Before you change a diaper, have the necessary equipment on hand. When changing the diaper, follow this step-by-step procedure.

- Use disinfectant for cleaning the changing table.
- Place the individual on a clean changing table or other appropriate surface. Do not leave the individual unattended.
- Remove the soiled diaper and place it in double bagged plastic in a covered pail. If the diaper is cloth and soiled with feces, leave it on the changing table until the individual leaves the area.
- If other clothing is soiled, remove it and place it directly into an identifiable plastic bag which can be secured and sent home or to the laundry.
- Cleanse the perineum (area between the buttocks and rectum) and buttocks thoroughly with soap and water. Use ointments and powders only when authorized and provided by a parent.
- Rinse and dry the skin before applying the clean diaper.
- Have the individuals return to what they were doing or assist him or her in returning.
- While wearing disposable plastic gloves, rinse and wring out in the toilet any cloth diaper soiled with feces. Use only disposable diapers unless the physician orders cloth diapers for a specific reason.

- After rinsing, place cloth diapers in appropriate receptacle.
- Remove gloves, discard them in an appropriate receptacle.
- Wash your hands after wearing gloves.
- Report abnormal conditions to appropriate person. Abnormal conditions may be:
 - Blood or streaks of blood on diaper
 - Watery, liquid stool
 - Mucus or pus in stool
 - Clay-colored stool
 - Skin rashes
 - Bruises or breaks in skin.
- Use a disinfectant to clean the changing table. Household bleach and strong chemical cleaners work well.

Adapted from *Managing the Student with Chronic Health Condition: A Practical Guide for School Personnel* by Pathfinder and the School Nurse Organization of Minnesota, 1986.

Section 6

Diet Monitoring

Common nutritional problems result in disorders in growth and weight gain. These may often be caused by poor eating skills or eating habits, or other unrelated factors. Diet monitoring involves helping the individual eat the right foods at the right times to maintain healthy weight, skin, and proper elimination. Some examples of conditions where diet has not been monitored appropriately are:

- Slower than expected linear growth might indicate that an individual is malnourished, has a chronic disease (e.g., kidney or heart disease), an endocrine problem, or a genetic or chromosomal abnormality (e.g., Down syndrome).
- Lack of appropriate weight gain a common problems found in individuals with special health care needs. Slow weight gain usually results from inadequate intake of calories. This may be due to poor appetite as a side effect of medication, feeding problems, or chronic illness. Inadequate intake of calories can cause an individual to be irritable and withdrawn. It can delay linear growth, motor abilities, and learning capacity.
- Children who gain weight too fast are more likely to be overweight as adults. This can lead to a number of health problems, including high blood pressure, diabetes, cancer, and heart disease. In addition, very young children who are obese

Discussion 1

Discuss these procedures. Ask students for questions and input. Give examples of situations where paraprofessionals may be asked to perform these procedures.

can show delayed gross motor development due to the extra fat their muscles must support. A number of individuals with disabilities have a tendency to be overweight, including those with Down syndrome, Prader-Willi syndrome, or spina bifida.

Equipment Needed

The equipment needed will vary depending on the type of diet monitoring taking place. Check each individual's diet plan and requirements for the equipment needed.

Student Considerations and Accommodations

- If you're working with an individual who is tube fed, this doesn't necessarily preclude oral feeding, but consultation with the physician or family will determine the quantity, type, and timing of oral feedings.
- Part of diet monitoring might involve dealing with an individual who has problems with constipation which is a very common problem. It can occur due to a number of factors including the individual's neuromuscular problem, inadequate fluid or fiber intake, lack of exercise, and/or drugs that decrease intestinal motility. If this occurs, refer to the section on constipation in the bowel care section, to help the individual deal with this problem.
- Other factors you may be involved in with dietary issues are gagging, vomiting, or rumination often resulting from over-feeding, food intolerances, improper feeding techniques, or gastrointestinal abnormalities. Occasionally an individual will gag or vomit to control his or her environment. Gagging, vomiting, or rumination can alter the acid-base balance of the body, cause irritation to the throat and mouth, and destroy the enamel on the teeth. If this should occur, try to talk to the individual to find out what is happening and why. Try to adjust the environment to accommodate the individual.

What to Ask

- If you notice that an individual's behavior seems to change and there doesn't seem to be any obvious reason, question the diet.
- If an individual has trouble eating with others or in certain environments, explore this with the individual and his or her family to modify the environment when needed.
- When the health office is to monitor the diet of an individual, make sure specific instructions are given in writing.

Adapted with permission from the authors from *Health Care for Students with Disabilities: an Illustrated Medical Guide for the Classroom* (1990), J. Graff, M. Mulligan-Ault, D. Guess, M. Taylor, & B. Thompson. Baltimore, MD: Paul H. Brookes.

Section 7

Glucose Monitoring

Individuals with diabetes have an imbalance of the amount of glucose in the blood. When this happens the individual can have behaviors that can affect his or her ability to concentrate and learn, or, in the worst case, can result in a coma and/or possible death. Glucose monitoring is a procedure that identifies the amount of glucose (sugar) that is present at any given time in the blood. Individuals will often have to check their glucose level during the work or school day. If the individual has an imbalance when the glucose is checked, then insulin must be administered. For more in-depth information about diabetes, refer to Chapter Eight.

Equipment Needed

Depending on the type of monitoring the individual uses, these may be types of equipment used.

- Alcohol pads
- A lancet
- A reagent strip (a small plastic with a pad on one end that changes color after exposed to blood)
- Glucose monitoring device

Student Considerations and Accommodations

- Most often individuals are encouraged to self-monitor blood glucose as part of their routine needs associated with insulin. This is especially encouraged for individuals who receive several insulin injections a day. Therefore, many are now taught how to check their own blood levels. You will probably be the location for their equipment to do this and to monitor the individual and the monitoring of blood glucose.
- If the individual doesn't have the coordination to perform the glucose monitoring for him- or herself, you will probably be called upon to do this during the day. The frequency will depend on individual need. That should be clearly stated in the individual plan for him or her.
- Help establish a reasonable schedule during the day for the individual based on the daily activities and his or her need.
- Provide the privacy needed for the individual (or you) to monitor injections.
- Help the individual remember to record the glucose level in a log or record. You may need to help do the recording for him or her.

Discussion 1

Discuss these procedures. Ask students for questions and input. Give examples of situations where paraprofessionals may be asked to perform these procedures.

- Watch the individual for signs of insulin reaction such as: shaking, sweating, dizziness, paleness, irritability, confusion, poor coordination, headaches, double or blurred vision, or numbness or tingling of the lips. If these occur, the individual should eat a snack containing fast acting glucose like a small box of raisins, a half cup of soda pop or fruit juice, or five small sugar cubes.
- If the individual is ill, the amount of physical activity and food should be decreased. The insulin dosage may need to be adjusted. Check this out with the individual and the family if you feel the individual is ill and occurs.

What to Ask

- Ask the individual what level of independence they are able to perform in their own glucose monitoring. If you're unsure whether this is accurate information, ask the licensed school nurse.
- Ask the individual what type of assistance they want from you. Respect the answer.
- Ask the individual or licensed school nurse what restrictions the individual should have in terms of activity, and food. Keep a record of this.
- Ask the individual if he or she has explained his or her situation to the person they spend the majority of the day with (teacher, co-worker, supervisor). Encourage him or her to do so.

Adapted with permission from the authors from *Health Care for Students with Disabilities: an Illustrated Medical Guide for the Classroom* (1990), J. Graff, et al. Baltimore, MD: Paul H. Brookes.

Discussion 1

These procedures for hand washing are extremely important for all health para-professionals to know and understand. Along with this background information, also discuss and refer to the additional information in Appendix O, which contains the flyers "Hand Washing Procedures" and "Hand Washing Steps". These would be useful for class participants to post in their work areas and to share with others.

Section 8

Hand Washing

Hand washing is the single most effective way to prevent the spread of infections. Hands are warm, moist, parts of the body that come in frequent contact with germs that cause contagious illnesses. Young children have not yet learned healthy personal habits; they suck their thumbs, put things in their mouths, and rub their eyes. Many individuals also like to handle animals and pets, which often carry a variety of germs. These habits can spread disease. Germs are easily spread when hands touch people, pets, and objects.

Caregivers must learn why, when, and how to correctly wash their hands and the individual's hands. Included in this section

are instructions on how and when to wash hands, for both staff and individuals, and pictures to demonstrate the correct hand washing procedure. Babies' hands can be washed with soap and running water using the same procedure that is used for older children and adults.

Soap

Liquid soap should be used in because often individuals do not have the dexterity to handle a bar of soap. Soap doesn't have to be antibacterial to be effective. It's the physical action of hand washing that removes soil.

Fingernails

It's important to keep fingernails short and clean. Fingernail brushes are effective in removing stool from under nails.

Gloves

- Gloves are *not* a substitute for hand washing.
- Single-use gloves must be disposed of after each use, and hands must be washed.
- Gloves should be worn by staff if they have open cuts, sores, or cracked skin, or if the individuals they are working with has open areas on the skin.
- Gloves should be worn when changing the diaper of an individual with diarrhea or a known infection that is spread through the stool.
- Pregnant women or women considering pregnancy may want to wear gloves when changing any diaper.
- Gloves *must* be worn for handling blood (nosebleeds, cuts) or items, surfaces, or clothing soiled by blood or bloody body fluids. Wear gloves when cleaning bathrooms, diapering area or any areas contaminated with stool, vomit, or urine.
- Either single-use or utility gloves may be used for cleaning and disinfecting contaminated items or areas.

Adapted from materials developed by Hennepin County Community Health Department with the support of the epidemiologists and child care consultants from the Minneapolis/St. Paul area state and local health departments, March, 1993.

Discussion 1

Discuss these procedures. Ask students for questions and input. Give examples of situations where paraprofessionals may be asked to perform these procedures.

Section 9

Skin Care

Skin reflects a condition of health. Important components include: a color that is normal for the individual, a smooth texture, no swelling, adequate elasticity, and sensation present to the degree that is normal for the individual. Healthy skin is characterized by having no bleeding or bruising; not being excessively oily or dry; having no breaks such as scratches or lacerations; and having no pressure sores, burns, or rashes.

Preventing skin breakdown is essential for those individuals who must remain in a wheelchair or in other positions for extended periods. It's far easier to prevent skin breakdown than to heal pressure sores. You will work with the LSN to implement procedures to prevent and/or treat skin breakdown.

Equipment Needed

- Gauze
- Ointments
- Alcohol

Student Considerations and Accommodations

- When promoting healthy skin in the individual with disabilities, consider discussing with the individual the student's degree of bladder and bowel control, nutritional status, level of activity, ability to distinguish sensations, and ability to communicate to others the sensations experienced. An individual who has limited control over bladder and bowel functioning needs a lot of support to have healthy skin.
- If the individual wears wet or soiled clothing the skin will not remain dry or clean. The constant presence of moisture can promote the growth of bacteria on the skin which can lead to infection. Help the individual express his or her needs in this regard so that skin conditions don't get out of hand.
- Based on the LSN's nutritional assessment, the SHP may work with the family to try to promote a healthy diet. Make suggestions about healthy foods the individual can buy, order, or cook that he or she would like to eat.
- Encourage the individual to be as active as possible. Exercise and activity will promote healthy skin. Brainstorm about ways the individual can be active, in spite of his or her disability.
- If the individual is in a wheelchair, remind him or her how important it is to be repositioned every so often to avoid pres-

sure sores. Set up a schedule with him or her for this to be done if help is needed.

Pressure Sores

Pressure sores develop in the following stages:

- Initially, pressure on the skin causes a reddening that disappears as the pressure is relieved. Such reddening often doesn't disappear after prolonged pressure is relieved. The skin becomes hardened and warmer than surrounding skin.
- A pressure sore develops where the skin continues to be reddened, hardened, and warmer than surrounding skin. The epidermis becomes broken and the dermis is exposed.
- In the third stage, an open sore develops as the dead tissue separates from the living tissue. The skin around the sore continues to be reddened and hardened and warmer than surrounding skin and there is drainage from the open sore.
- In the last stage, the open sore becomes deeper and has a foul smell. There may or may not be drainage present.

What to Ask

- Ask the individual if he or she has any allergies that may be causing the condition. Report allergies to the LSN or note them on the health record or emergency card.
 - Help with skin care problems may require changing dressings. Ask the individual what help and support he or she may need in this. Make sure you know when these changes should take place. This information should be available on the IHP.
 - Report any skin concerns to the LSN. Optimal levels of activity may be encouraged as part of a proactive skin care program on the IHP. Decreased activity can result in increased opportunities for the student to experience pressure on skin surfaces.
 - The skin underneath braces and splints or wheelchair seats should be checked *daily* or as noted in the IHP to identify persistent red spots. Ask the individual if he or she has noticed any sores and make sure he or she is moving and shifting in the chair often. If the individual cannot initiate movement to relieve the discomfort, methods need to be included in the IHP to assist the individual in communicating with others.
 - If a pressure sore is being treated, it needs to be written on the IHP by the nurse. Ask for adequate supplies to perform the treatment. Eliminating pressure from the sore to prevent further breakdown is of utmost importance. A regular schedule for repositioning the individual will be established using those positions that best allow the student to continue with other activities while avoiding pressure on the existing sore and sustained pressure on other areas at risk of developing sores.
-

- Observe the healing process and report to the LSN. Ask individuals how they feel and if they seem to be healing. If an individual has a sore that doesn't heal and that progresses in size, the potential for blood poisoning exists. This condition indicates that bacteria have entered the blood stream. If not treated with antibiotics, the infection can progress and cause an overwhelming infection and death.

Parts of this section were adapted from *Health Care for Students with Disabilities: an Illustrated Medical Guide for the Classroom*. J. Graff, et al., Baltimore, MD, 1990, Paul H. Brookes Publishing Co. Reprinted with permission from the authors.

Section 10

Toileting Procedures with Individuals Who Use Wheelchairs

Discussion 1

Discuss these procedures. Ask students for questions and input. Give examples of situations where paraprofessionals may be asked to perform these procedures.

Individuals who need help toileting may each have their own way of completing this task. You can follow these suggested steps for helping an individual out of the wheelchair and onto the toilet:

- The SHP should wash his or her hands at both the beginning and end of toileting.
- Wheel into stall.
- Lift and swing tray away.
- Position chair next to toilet.
- Lock brakes.
- Unfasten seat belt.
- Unfasten pants.
- Push pants down to buttocks.
- Lift buttocks off chair seat (doesn't need footrest to push up on for pants down).
- Push pants down over buttocks to knees.
- Lower hips to chair seat.
- Push underwear down to buttocks.
- Lift buttocks off chair seat.
- Push underwear down over buttocks to knees.
- Lift buttocks off chair seat.
- Lower hips to chair seat.
- Swing away footrest (reposition chair as necessary).
- Right arm grabs bar.

- Left arms hold the left wheelchair armrest, then toilet seat.
- Reach down to toilet seat with right arm.
- Pull self forward in chair.
- Feet on floor pull forward & pivot onto toilet.
- Position self securely on toilet (doesn't use footrests to push pants down).

These steps should be followed to move from the toilet back to the wheelchair:

- Provide any necessary assistance in wiping.
- Flush toilet.
- Pull underpants and pants up over knees.
- Grab transfer bar with right arm.
- Reach across and grab chair seat with left arm and pull self forward.
- Feet on ground, pull forward and up; pivot into chair.
- Hold onto chair armrests with each hand and position self securely in chair.
- Unlock brakes.
- Wheel back from toilet (far enough to clear swinging footrests).
- Lock brakes.
- Swing footrests into place (pull pants up from underneath shoes if necessary).
- Pull underwear up as far as possible.
- Lift buttocks off seat (by pushing with leg and arms).
- Pull underwear up over buttocks to waist.
- Lower hips to seat.
- Pull pants up as far as possible.
- Lift buttocks off seat.
- Pull pants up over buttocks to waist.
- Lower hips to seat.
- Straighten underwear and pants if needed.
- Assist tucking in shirt.
- Fasten pants.
- Fasten seat belt. Be sure hips are all way back in chair so trunk is vertical and no greater than four inches of thigh are forward of chair seat.
- Swing tray back into place.
- Unlock brakes.
- Wheel out of stall.

Summary

Along with learning about disabilities, it's also essential that SHPs know special personal care skills to help meet the needs of the individuals with whom they work. The skills included are those often used in caring for individuals with a disability. These skills will be demonstrated and practiced in class. The LSN you work with will provide you with a review of the skill and the opportunity to re-demonstrate the skill. The SHP may perform some of the skills as part of his or her job responsibility. Others of them are delegated from the LSN. With good communication and understanding, the LSN and paraprofessional will provide safe, quality care for their clients.

Questions to Ponder

- Safety is a primary factor in performance of personal care skills. Why?
- If your child had a disability what would you (as a parent) expect of the LSN and SHP?
- Of the skills discussed, which two are the most essential for your safety and the individual's safety? Why?

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Chapter Ten

Selected Health Procedures: Specific Instructions

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Introduction

The following are brief descriptions of additional types of care that you may eventually provide for individuals. These are all types of care that should only be given after receiving specific instruction and training from the supervising nurse. For that reason, these descriptions are provided as background information only.

Section 1

Catheterization

An individual may have a catheter inserted for many different reasons. Urinary catheterization is often done to:

- Relieve urinary retention.
- Obtain a sterile urine specimen.
- Measure the amount of residual urine in the bladder.
- Obtain a urine specimen when a specimen cannot be secured satisfactorily by other means.
- Empty the bladder before and during surgery and before certain diagnostic procedures.

A catheter that will remain in place is called an *indwelling retention*. The majority of the time an indwelling catheter is placed temporarily. An indwelling catheter consists of a long, narrow, flexible tube with two holes in the end that is inserted into the bladder. This same end has an area that inflates to the size of a very small balloon when filled with sterile water. The sterile water is injected via a pre-filled syringe through a lumen on the distal end of the catheter specifically made for this purpose. The indwelling catheter is connected to wider tubing which is attached to a plastic bag that serves as the collecting container for urine.

An individual who requires catheterization during school has a scheduled time to do this. He or she will need a private area for the catheterization with a sink for proper cleanliness. Catheterization procedures differ for males and females and from person to person. Some individuals catheterize themselves and won't need the SHP to facilitate the procedure. The procedures include positioning, cleansing the area, insertion of the catheter, draining the bladder, removing the catheter, and clean-up.

Discussion

Explain to the class that these descriptions are only brief ones because they are procedures that must be taught thoroughly by a nurse and should be performed only under a nurse's supervision. Discuss these procedures and answer any questions.

Section 2

Colostomy and Ileostomy

A colostomy or ileostomy provides a way for a person to eliminate feces without passing it through the rectum. Whether a person has a colostomy or an ileostomy is determined by the portion of the intestinal tract that has been involved in disease, disability, or accident. A colostomy or ileostomy is performed when there has been obstruction or blockage in the intestines and passage of the contents in the intestines is prevented. Either a colostomy or an ileostomy may be temporary or permanent. After a colostomy or ileostomy have been surgically performed, the individual no longer has the ability to retain feces in the rectum or pass feces through the rectum and out the anus. Feces are, instead, eliminated through a hole called a *stoma* that is created through an opening in the abdomen. A pouch is attached over the stoma for collection of fecal material as it is eliminated from the intestines.

Care for persons with colostomies or ileostomies is usually provided at home. If students need assistance at school, the SHP should refer to the IHP implement the planned activity, notify the LSN, and record the action taken.

Section 3

Oxygen Therapy

Oxygen may be ordered by a physician to help an individual breathe. Depending upon the individual's condition, the physician will determine how much oxygen the individual should receive. Many individuals may require oxygen in home, at school, or work. Some of these individuals may have infections involving the lungs, (for example: pneumonia), loss of lung elasticity, loss of functioning lung tissue due to disease, diseases of the nervous system (for example Guillan-Barre, multiple sclerosis, etc.)

The health paraprofessional *does not* administer oxygen.

To help prevent fires the following precautions should be taken when using oxygen:

- Store oxygen tanks in an upright position in a cool area.
- Keep oxygen away from heat and electricity.
- Do not smoke when oxygen is in use.
- Place "No Smoking" signs in conspicuous places.
- Open flames, such as candles, matches, or stoves aren't allowed.
- Avoid use of flammables such as oils, alcohol, synthetic clothing, and wool blankets.

- Check to see that the electrical equipment used in the room is in good working condition and doesn't emit any sparks.
- Turn off flow regulators when they aren't in use to avoid oxygen leaks. (This should be done only if the health paraprofessional has been taught by the supervising health nurse.)
- Keep fire extinguishers available and in proper working order.
- Use of a humidifier will help reduce static electricity and the drying effect of oxygen.

Section 4

Respiratory Therapy

Individuals sometimes receive a form of respiratory therapy called *intermittent positive-pressure breathing* (IPPB) which provides a specific amount of air, oxygen, water, or medication under increased pressure to the respiratory tract. This device forces deeper inspiration by positive pressure inhalation and then permits passive exhalation. The pressure varies according to the person's needs. Assisted ventilation is used for persons who have respiratory disorders when periods of deeper inhalation would be helpful to further aerate the lungs or to move secretions. Pressure for the IPPB is supplied by the machine, which uses compressed air or oxygen. The air or oxygen is forced through a nebulizer containing distilled water or medication. The person who is having assisted ventilation inhales the mist through a mouthpiece or face mask. In many instances the person controls the rate of the machine by his breathing; in others the rate is controlled by the machine. Treatments are usually done twice a day, in the morning and at night.

The SHP doesn't administer respiratory therapy, but may be asked to provide skin care for persons who use a nasal cannula or mask. Water soluble lubricants can be applied to the skin - oil based lubricants can damage the mask or tubing. New tubing can add to the individual's comfort: encourage the individual or his or her family to change tubing on the recommended schedule.

Section 5

Tracheostomy

A tracheotomy is an incision into the trachea or windpipe, performed to create an opening in the trachea to accommodate a tube thorough which the individual will breathe. A tracheotomy is usually done to provide an airway that bypasses an obstruction in

the upper respiratory area.

The tracheostomized person is unable to speak, unless the tracheostomy tube is closed off. People with tracheostomies may initially be very frightened and anxious and need a lot of support and reassurance that their needs will be met promptly and efficiently. Other means of communication are necessary between the individual and others.

Once the opening has been made into the throat, a curved tube called a *cannula* is inserted and remains there to keep the airway open. The cannula may be metal or plastic and consist of either one or two tubes. Some persons who have had a tracheostomy for a very long time may have only an open hole in the neck area that remains open on its own. Since the tracheostomy tube serves as the person's airway, care must be taken to prevent the inspiration of foreign material into the unprotected tracheostomy tube. For this reason cotton balls, loose threads from gauze, or other foreign bodies must be kept away from the tracheostomy opening. Because the nasal passages are bypassed, the normal humidification process must be artificially provided for the person with a tracheostomy. This is usually accomplished by a humidifier or attaching a humidifying device.

The person with a tracheostomy may lead a normal life and become involved in almost any activity, except swimming.

The tracheostomy tube is usually held in place by two ties that attach to the sides of the tube. If there are complaints of discomfort around the tube or from the ties, the health paraprofessional should report them to the supervising health nurse. There may or may not be a dressing around the tracheostomy. An emergency care plan will be completed with activities for the SHP and/or other school staff to follow should the tracheostomy tube become dislodged.

Section 6

Tube Feeding

There are many reasons why individuals with disabilities may not be able to eat by mouth, some of which include inadequate sucking ability, extreme difficulty chewing and swallowing, or frequent episodes of pneumonia resulting from stomach contents or formula being drawn into the lungs. There are two types of tube feeding described here: nasogastric tube feeding and gastrostomy tube feeding.

A nasogastric tube (NG) is extended through the nose, down the esophagus, and into the stomach. The individual receives nutrients in a liquid form through this tube. This type of tube is used as a short-term intervention. Liquid nutrients may be passed

through the NG by one of two methods: the bolus method, which allows the flow to happen within a few minutes, or the intermittent gravity drip method which allows formula to drip slowly over a twenty to thirty minute period from a hanging container. These two methods are used when individuals can tolerate fairly large amount of fluid nutrients over a relatively short period of time.

A gastrostomy tube is extended directly through the abdomen into the stomach. The individual receives liquid nutrients through this tube, as he or she would through the NG tube. The gastrostomy tube is really a polyurethane or silicone tube that is soft and flexible and about eight to twelve inches long. The tube is inserted through the abdomen wall into the stomach and is held in place by suture. A clean gauze dressing is often taped around the tube to protect the opening and absorb any leaking. If this irritates the skin, the gauze is not used. If a button gastrostomy is used, a short tube is inserted into an established opening in the stomach. The button fits closely to the skin on the abdomen and has a small plug that is removed for feedings.

The difference between the NG and the gastrostomy tube is that the purpose for the gastrostomy is long-term or permanent feeding, not short-term feeding as with the NG. Liquid nutrients may also be passed through the gastrostomy tube by one of the two same methods as the NG: the bolus method, which allows the flow to happen within a few minutes, or the intermittent gravity drip method which allows formula to drip slowly over a twenty to thirty minute period from a hanging container. These two methods are used when individuals can tolerate fairly large amount of fluid nutrients over a relatively short period of time.

Section 7

Ventilators

Any individual with a condition that alters his or her ability to breathe independently may require ventilatory assistance. Ventilators breathe for people until they can breathe on their own. Ventilators have most often been used with persons in the intensive care unit (ICU) of the hospital. Now ventilators are also used as a means of respiratory support in home, work, and schools.

Persons who require a ventilator may be those who have conditions such as pneumothorax (collapsed lung), ARDS (adult respiratory distress syndrome, where parts of the lung become increasingly stiff and noncompliant), COPD (chronic obstructive pulmonary disease, where lungs are chronically overinflated and inelastic), persons who hypo-ventilate after thoracic or abdominal surgery; persons who may be obese or debilitated; persons with nonfunctioning respiratory regulatory mechanisms.

The SHP will not work with the ventilator without training and supervision from the LSN.

Adapted with permission from the authors from *Health Care for Students with Disabilities: an Illustrated Medical Guide for the Classroom* (1990). J. Graff, et al. Baltimore, MD: Paul H. Brookes.

Summary

The select health procedures discussed in this chapter are those that may be delegated to the SHP from the LSN. Each situation will be assessed and evaluated separately. (Refer to the chapter on delegation to review the importance, responsibility, and legal implications of nursing delegation.) Since the individual's needs have to be met regularly, these procedures are often done in school and they're usually performed by the nurse. These procedures have been included here to provide basic information about the procedure and to increase awareness and understanding of both its necessity and steps required to carry it out. Having this knowledge will help the SHP understand the individual's needs and will provide a basic understanding if the LSN delegates the procedure to the SHP.

Questions to Ponder

- Why are these procedures performed by the LSN?
- What issues does the LSN consider if these procedures are delegated to the SHP?
- As a SHP performing these select procedures, what concerns will you have in mind?

11

Chapter Eleven

Medication Administration

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Introduction

Medications are used to help a person recover or maintain normal body functions. They can be very strong: medication taken incorrectly may not have the desired results or have serious – or even fatal – negative effects.

The main reasons a health paraprofessional would be administering medications are to relieve symptoms, treat an existing disease, or promote health. Many students with disabilities require medications throughout the school day and wouldn't be able to come to school without help and support with medication.

If delegated by the LSN, the SHP may administer prescription or as over-the-counter (nonprescription) medications when requested by parents. Medications that are prescribed by a physician for a particular individual should never be taken by anyone else. An example of a prescribed medication is penicillin, while Tylenol is a nonprescription medication.

As the SHP, you may administer medications in a variety of ways orally, rectally, topically, in the eyes or ears, and in the nasal passages.

Before administering any medications, review and follow the policies of the school district related to approval and consent for medication administration. These generally include parents' requests to give medication (it's always helpful to talk this over with parents first), physicians' written approval or request for administration of medication, and a secure place to store medications. The medication container must have the individual's name on it, the dosage, the frequency of administration, and the prescribing physician's name. There should be a system for recording what medications and for whom are being kept in the health office at all times.

Section 1

Properly Administering Medication at School

Whenever possible, the parent or guardian should make arrangements so that it's not necessary for school personnel to administer a medication to a student. However, there are cases when a student's health could be compromised by not getting medication during school hours. In response, school districts need written policies and procedures for administering prescribed medications. These help to ensure that the student – who must use medication to treat a disability or illness – will attend school.

Discussion

This chapter is very important for students to understand. Be sure to spend time going through all aspects of medication administration to students so they clearly understand what the role of the health paraprofessional should be and what the role of the licensed school nurse should be.

Be sure students understand the preliminaries they must follow before administering medications. Then they should know the procedures to be followed very clearly.

Take Care of Preliminaries

After you have been authorized to administer medications by the LSN and have been instructed by the school nurse but before administering any medication, the LSN will:

- Identify students who require medication. The school nurse, principal, teacher and other school personnel should know which students require medications during the day. If the school doesn't have a school nurse, the principal should assume responsibility, with the parents.
- Get a written prescription. Require this from the physician. The prescription should indicate the necessity of administering medication during school hours.
- Get a written statement from the parents. This should request and authorize the designated personnel to administer the medication prescribed by the physician.
- Get a duplicate bottle. Parents should ask the pharmacist to prescribe duplicate bottles of the medication. One bottle should be kept at home, the other at school. Both bottles should contain the name and telephone number of the pharmacy, the student's identification, name of the physician, the name of the medication and the dosage to be given.
- Keep a list of students on medication during school hours in a central place. For each student, include the name of the medication, the medication dosage and times medication should be given. Also include information on why the student is taking medication and the route medication is to be given.
- Let the school nurse supervise medication administration. Medications should be administered under the direct supervision of the school nurse or other health qualified professional. If you, as a health paraprofessional, are the designated person, you should have:
 - Knowledge about the effective use of medications and their side effects.
 - Knowledge of the condition for which the medications were prescribed.
 - The ability to understand coping mechanisms used by students who must take medication more than once a day.
 - The ability to properly administer and record medications given in school.
 - Ability to observe, evaluate and report the student's reaction to the medication in school – including expected or adverse reactions.

To properly administer prescribed medication, the school nurse – or staff member directly supervised by the school nurse – must follow these steps:

- Check the bottle to assure the correct medication is given to the student. Prescribed medication bottles should bear the individual's name; the date the prescription was filled; the name, address, and phone number of the pharmacy; the prescription number; the drug name, dosage, and frequency; physician's name; and any special storage instructions.
- Check the prescription to assure the proper dosage is given in the prescribed way. Make sure it's the right medication for the individual.
- Wash hands before and after administering any medications.
- Inform the appropriate school staff of the potential benefits and side effects of the medication being taken by students.

Administration of Types of Medications

- **Capsules & pills:** Pour directly into a paper cup without touching the medication and assist the individual in getting a cup of water.
- **Liquids:** Shake if required. Pour medication out of the side opposite the label, holding measuring container at eye level.
- **Topical medication for the eyes:** To clean the eyes, use a clean wipe for each eye. Have the individual lie down and look up. Retract the lower lid, approach the eye from behind, outside the field of vision. If ointment, apply gently near the center of the lower lid. If drops, apply gently near the center of lower lid. Do not touch lid with dropper or allow closer than one inch above the eye. Have individual close eyes for two minutes.
- **Topical medication for the ears:** Tilt the head so ear opening is as horizontal as possible. Administer the prescribed number of drops and have the individual remain with his or her head tilted for two to three minutes. If the other ear is also to have drops, wait five minutes and apply them to the other ear.
- **Topical medication for the skin:** Cleanse the area first. Then use clean tongue blade to apply ointment; discard blade, then re-apply a bandage.
- **Suppositories:** Have individual lie down on stomach or on back with knees pulled up, whichever way is more comfortable. Remove suppository from container and generously lubricate it. Expose the anus with one hand and gently insert the suppository with the other. Use the forefinger to advance it once it has passed through the anus but no farther than your first digit. You may have to hold your finger against the anus briefly to prevent the rectum from expelling the suppository reflexively. Make sure the individual is comfortable and instruct him or her to lie quietly for the time indicated.
- **Inhalers:** Help the individual prepare the inhaler. Pressing harder or longer on the activator doesn't change the amount

of medicine delivered. Follow the manufacturer's instructions for administration.

- Record the medication given on the medication record.

Regarding All Medications

- Remember the "six R's" of administering medication – they point to factors you should remember when administering medication to a student: right name (of student); right drug; right dose; right time; right route (by mouth, injection, etc.), and the right record.
- After each administration of the medication, record the date, time, and your signature on the student's medication log.
- If medication is not given, record whether the student was absent, refused, or do not come to the health room.
- Discuss any problems about student compliance with the licensed school nurse.
- Report any adverse reaction noted to the licensed school nurse immediately and take appropriate action. Record on the log what occurred.
- Always return any medication to the locked storage area immediately after administration.
- Injected medications are given only by the LSN.
- School health paraprofessionals administer medications when authorized by a licensed school nurse. The nurse gives guidelines and directions for the health paraprofessional to follow.
- Do not give over-the-counter medications unless the parent requests it in writing and the medication is provided in the original container. *Never violate this rule.*
- Observe, evaluate, and report the student's health status and reaction to the medication at school. Give this information to the parents or guardians – and the student's physician if parents have given approval to do so.
- Store medication in an appropriate place. Keep it locked, and make sure that only designated school personnel have access. If you see any student self-administering medication for which the school has no authorization, report this to the LSN.

Adapted from materials developed by Cyndy Schuster, M.P.H., R.N., C.S.N.P.

Summary

Administration of medication is a nursing task that can seem very easy. However, it's more than just physically giving a tablet or capsule of medication to someone – it includes the responsibility of

understanding the action of the medication's actions, indications, and counter-indications or side effects. Giving a medication to another also carries ethical and legal implications. This procedure, as well as the procedures discussed previously, is often performed by the nurse. The nurse often delegates this responsibility to the SHP and the decision is based on the nurse's judgement.

Questions to Ponder

- What types of medications may the SHP administer with delegation of the LSN?
- What legal issues must be considered when giving medication to another person?
- Minnesota statutes say that schools must have policies for administering of medications to individuals in school. Why is this important?

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Appendix A

People First Language

By Kathie Snow, Parent Assistance Specialist,
Northeast Texas, Fort Worth, PATH Project

Your child is not handicapped. Your child is not disabled. Your child has a disability.

A handicap is an obstacle which society imposes on a person with a disability, i.e., inaccessible transportation or buildings, stairs instead of elevators, no curb cuts where needed, etc.

The Disability Rights Movement is upon us... it had a slow start, but momentum is increasing daily.

Consider this Public Law 94-142, the legislation which guarantees an appropriate education for children with disabilities, was the culmination of a lawsuit filed in 1971 by the Pennsylvania Association for Retarded Citizens on behalf of their children who were not being served by the educational system. PL 94-142 was enacted in 1975. Changes have been occurring, off and on, since that time.

Consider what happened in 1990. In early 1990, the Senate Subcommittee on the Handicapped, chaired by Senator Tom Harkin, (D-Iowa), changed its name to the Senate Subcommittee on Disability Policy.

On July 26, 1990, President George Bush signed into law PL 103-336, the Americans with Disabilities Act (ADA) Notice it was not called the *Handicapped Americans Act*! This sweeping legislation mandates equal opportunities for persons with disabilities, persons who had previously been discriminated against in employment, housing, transportation, and many other areas of daily life.

In 1990, PL 94-142 Congress reauthorized and renamed the Education of All Handicapped Children Act (EHA). It is now PL 103-476, the Individuals with Disabilities Education Act (IDEA).

Isn't it great? But we've still a long way to go. Government cannot legislate morality or values or feelings. Before our children, and others with disabilities, are viewed as truly equal members of our society, our language and our values must be changed. Persons with disabilities must be perceived as valuable, contributing members of society.

The Civil Rights Act was passed in 1964, but it took years before the law really seemed to have an effect. During that time, a long-used degrading term finally became *Negro*, which became *Black*, which has become *African-American*.

Now, it's time to change the other language used in society. Labels degrade. Labels evoke negative pictures in your head. Labels don't address individuality - they lump people together! Disability labels focus on the disability - not on the person and his abilities!

Persons with disabilities want dignity, respect, and the opportunity to succeed. But those things are hard to achieve when you're saddled with a label: handicapped, disabled, crippled, autistic, blind, etc. The solution is *people first language*. What is it? It focuses on the person first, the disability last. How do you know what it is? It describes what the person *has*, not what he *is*. It's easy – just use your imagination:

Persons with disabilities... a child has cerebral palsy... my sister has a mental disability (or mental *impairment*)... my child has a developmental delay.

Many organizations are already making these changes. Others haven't, and they need a little push. Get on the bandwagon, and use your power as a parent, as a member of a support group, to ask for these changes. Write letters. Talk to people.

When you hear an incorrect description, gently correct the user and explain why it's important to use *people first language*. When it comes to basics, PFL is just good manners: treat others as you would like to be treated.

As our society's language changes, when we talk about people first, perceptions will change, and society's acceptance, inclusion, and respect for persons with disabilities will become a reality. History tells us that it takes at least one generation between the time an idea is born and the time it actually becomes incorporated into our society.

You may be advocating on behalf of one child, but your advocacy affects many, many others. Advocacy means change, and change creates tension. Don't be dismayed if you have to correct the same people many times; old habits die hard. But old habits do go away when they're replaced by good habits. Change your habits first, then work on others.

The time for people first language is *now*. Do it for one person – do it for the world!

Editor's Note: Partners Resource Network is in the process of adhering to people first language in all our publications. However, we often use names of organizations and programs that do not use PFL and our materials may include publications produced by sources that do not use this language. In these instances, we must use the official names and titles regardless.

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Appendix B

Finding Right Words is Still a Big Struggle for "Disabled People"

By Dianne B. Piastro

Q: Please! There is no such thing as handicapped parking.
Why do you keep writing this? It is parking for the handi-
capped/disabled.

D.P., Syracuse, N.Y.

A: You're one of a growing number of people trying for gram-
matical precision, and I share your frustration. But, unfortunately,
the term "handicapped parking" has been codified into state and
federal laws since its inception. The recently implemented Ameri-
cans with Disabilities Act refers to it as "accessible parking," but
changing existing statutes and parking lot language will probably
take a long time.

However, you've opened a Pandora's box with your assertion
that I should say it's "parking for the handicapped/disabled."
When individuals are referred to as "the handicapped" or "the
disabled", they are defined in terms of a condition only. Today's
preferred phrases are more humanizing and embrace the person
by using variations of "people with disabilities" whenever possible,
though "disabled persons" also is used.

Generally, people think *handicapped* and *disabled* are synony-
mous, but they aren't. A handicap is defined as a restriction or dis-
advantage in a contest.

Many people incorrectly think it comes from a time when beg-
gars with caps in hand were the only disabled people seen in pub-
lic. In fact, it comes from a 17th century English gambling game
in which players thrust their hands into a cap to retrieve objects –
the "winners," rather than "losers" were penalized. That is prob-
ably why the word *handicap* became associated with adding weight
to superior horses to equalize a race, and with giving sports con-
testants advantages to equalize their chances of winning.

Later, *handicap* came to mean a barrier to performance, an ob-
stacle in our surroundings. For example, steps are a handicap to a
wheelchair user. A voice-operated telephone handicaps deaf and
speech impaired persons, but a TDD equipped telephone enables
them to send and receive typewritten messages; people who are
blind are handicapped by a printed book, but not a recorded one.
Thus, the handicap is not the inability to walk the deafness, speech
impairment or blindness, it is the inaccessible, unaccommodating
environment or lack of appropriate equipment.

On the other hand, the word *disable* means "to make unable; to deprive of normal strength or power." "Disability" is "that which disables, as illness." These *Webster's New Twentieth Century Dictionary* definitions hold no punches, but they do not imply that having a disability negates a person's other abilities.

When you have a disability, one or more of your functional abilities is weakened, which means you are either unable to do certain things or you do them another way. Unlike disabled cars, people are resourceful, multifaceted beings who can, and do, continue to function when they have a disability.

Carol Gill, a Chicago-based clinical psychologist who is disabled, sums it up this way: "People think it's the word itself that is difficult but it isn't. Disabled and disability are just plain speaking. We belong to one of the few groups of people in the world who can be honest about not being able to do certain things as everyone else does them. There is power in being able to say, 'So what? I can't do this particular thing, but I'm OK.' The fact that someone can't, for example, walk without assistance and gets around in a wheelchair, doesn't negate the validity of that person's value as a human being."

Nationally, disability, rather than handicap, is evolving as the word of choice. Organizations and agencies are changing their names, and legislation no longer contains the word *handicapped*. Like African-Americans, who chose to use the once pejorative word *black* as an affirmation of pride and dignity during the civil-rights era of the 1960s members of the disability movement are embracing a negative word and denying the outdated stereotypes and stigma attached to it.

But even though this trend has been gaining momentum for more than a decade, most news media coverage still perpetuates the image of disabled people as *suffering*, *stricken*, *afflicted* and *victims* who are *crippled* or *wheelchair-bound*. Being associated with the pictures those words paint isn't easy.

Such euphemisms as *physically challenged* are expressions of denial that trivialize our experience, and people with disabilities in Michigan are called handicappers. So, our movement's term for self-identification is not yet unanimous, but we're a tenacious group.

Reprinted with permission from the author from the February 2, 1992 Minneapolis *Star Tribune*.

Appendix C

ADA Requirements Fact Sheet

Employment

- Employers may not discriminate against an individual with a disability in hiring or promotion if the person is otherwise qualified for the job.
- Employers can ask about one's ability to perform a job but cannot inquire if someone has a disability or subject a person to tests that tend to screen out people with disabilities.
- Employers will need to provide "reasonable accommodation" to individuals with disabilities. This includes steps such as job restructuring and modification of equipment.
- Employers do not need to provide accommodations that impose an "undue hardship" on business operations.
- Who needs to comply:
 - All employers with twenty-five or more employees must comply, effective July 26, 1992.
 - All employers with fifteen to twenty-four employees must comply, effective July 26, 1994.

Transportation

- New public transit buses ordered after August 26, 1990, must be accessible to individuals with disabilities.
- Transit authorities must provide comparable paratransit or other special transportation services to individuals with disabilities who cannot use fixed route bus services, unless an undue burden would result.
- Existing rail systems must have one accessible car per train by July 26, 1995.
- New rail cars ordered after August 26, 1990, must be accessible.
- New bus and train stations must be accessible.
- Key stations in rapid, light, and commuter rail systems must be made accessible by July 26, 1993, with extensions up to twenty years for commuter rail (thirty years for rapid and light rail).
- All existing Amtrak stations must be accessible by July 26, 2010.

Public Accommodations

- Private entities such as restaurants, hotels, and retail stores may

not discriminate against individuals with disabilities, effective January 26, 1992.

- Auxiliary aids and services must be provided to individuals with vision or hearing impairments or other individuals with disabilities, unless an undue burden would result.
- Physical barriers in existing facilities must be removed, if removal is readily achievable. If not, alternate methods of providing the services must be offered, if they are readily achievable.
- All new construction and alterations of facilities must be accessible.

State and Local Government

- State and local governments may not discriminate against qualified individuals with disabilities.
- All government facilities, services, and communications must be accessible consistent with the requirements of section 504 of the Rehabilitation Act of 1973.

Telecommunications

- Companies offering telephone service to the general public must offer telephone relay services to individuals who use telecommunications devices for the deaf (TDDs) or similar devices.

This document is available in the following accessible formats: braille, large print, audio tape, electronic file on computer disk, and electronic bulletin board. Call (202) 514-6193.

For more information about the ADA, contact:

U.S. Department of Justice, Civil Rights Division, P.O. Box 66118, Washington, DC 20035-6118, (202) 514-0301 (voice), (202), 514-0381 and (202) 514-0383 (TDD)

Appendix D

What the ADA Means for People with Developmental Disabilities

By Deborah L. McFadden and Edward P. Burke

With today's signing of the landmark Americans with Disabilities Act, every man, woman, and child with a disability can now pass through once-closed doors into a bright new era of equality, independence, and freedom.

President George Bush

As we stood on the south lawn of the White House and heard the President speak these words over two years ago, we felt that a new era of opportunity and hope had dawned for people with developmental disabilities all across America. The struggle to pass the Americans with Disabilities Act (ADA) had been a long one. Strong coalitions of disabilities rights groups had been forged after decades of individual self-interest. Wary business leaders and lobbyists had been educated and negotiated with, something we in the disability rights movement were not accustomed to doing. Members of the Congress had been convinced that the passage of the ADA would be good for all Americans, not only the minority of Americans with disabilities. The challenges had been great. And, standing amidst thousands of fellow advocates as the President signed the ADA, the taste of victory was sweet: people with disabilities would now have full access to the American Dream.

Almost immediately after this historic signature ceremony at the White House, we began to hear that some disability advocates (particularly leaders in the field of mental retardation) were wondering aloud if the ADA "really" applied to their constituencies. We were somewhat surprised at this reaction from individuals whose associations had been so active in framing the Act and securing its passage. We sought to assure them that all Americans with disabilities were fully covered under the Act, including people with mental retardation and other severe disabilities. Indeed, in comparing the definition of "developmental disability" in this Act with the definition of "disability" in the ADA, we find it inconceivable that anyone who qualified as "develop mentally disabled" under the DD Act (wherein it is required that a person have "substantial functional limitations in three or more... areas of major life activity") would be considered "ineligible" for coverage under the ADA (wherein it is required that a person has an "impairment that substantially limits one or more of the major life activities").

We must all understand from the outset that people who have developmental disabilities are, in fact, covered under the Americans with Disabilities Act and have all the rights and protections guaranteed under the Act. We must also understand that the challenge of making the ADA have a significant impact on the lives of persons with developmental disabilities does mean many more years of hard work, public education, and forceful advocacy for us all.

For example, the ADA promises that, at present, employers with more than twenty-five employees cannot discriminate against qualified people with developmental disabilities in employment. This covers areas such as recruitment, hiring, job assignments, pay, layoff provisions, firing, training, promotions, benefits, and leave policy. But, to assure full benefit of this promise much must be done in expanding public attitudes about the meaning of "qualified" and in teaching and supporting people to reach their fullest ability to demonstrate their qualifications.

The ADA also promises that people with developmental disabilities will have access to nearly every conceivable public facility such as restaurants, banks, hotels, shopping centers, and offices. However, many individuals need support and opportunities to take advantage of this provision. Approaches to service delivery that institutionalize and isolate persons with developmental disabilities reflect denial by developmental disabilities specialists of access to the very opportunities society as a whole is ready to provide.

The ADA promises that people with developmental disabilities will have significantly increased access to transportation services. But such promises can be meaningfully fulfilled only if the developmental disabilities service system is willing to accept the benefits of public access over the convenience of specialized vans and buses.

Finally, the ADA promises that people with developmental disabilities that involve hearing losses or speech and language impairments will have access to mainstream telecommunications networks. But, in order for persons with developmental disabilities to benefit from such access, service providers must commit to the fullest possible development of communication abilities.

What will all of this – the letter and spirit of the ADA mean for people with developmental disabilities? First, we can foresee a day in the not-too-distant future when it will be virtually unthinkable for children with developmental disabilities to be educated anywhere but in typical neighborhood schools. Even "special transportation" will fade into obscurity as young people with disabilities travel to and attend school with their siblings and typical age peers.

Second, we see a day in which the process of moving from school to work or further education will become a natural and much smoother transition. Students with disabilities will do what their typical peers hope to do: go on for further education or get a job. "Waiting lists" for such opportunities will be unthinkable.

Third, we see a future where people with disabilities live in typical housing, not in institutions or "group homes", but in apartments and typical houses – some as renters and some as owners.

Lastly, we see a future where people with developmental disabilities will be much more involved in the social and financial lives of their communities. They will be viewed as "givers" as well as "receivers", as contributors of their time and talents to their communities. They will help to make their communities better places for everyone to live, places where it is "OK" to be different.

For all of this to happen, people with developmental disabilities and their advocates must see themselves as active players in defining what the ADA will eventually mean to our society. It is critical that people with developmental disabilities, their advocates, and professionals establish and demonstrate new and creative meanings for terms such as "qualified," "reasonable accommodation," and "readily achievable." While some have criticized the ADA as "vague" in its definitions of terms such as these, we see this as an opportunity for people with developmental disabilities and their advocates to test the limits of creativity in developing new avenues of opportunity for the full participation of people with developmental disabilities in society.

Being creative does not necessarily mean being expensive for businesses and communities. Many of the "technologies" that can help people with severe disabilities function and flourish in the workplace have already been "invented": job coaches, personal care attendants, augmentative communication aids, and the like. Many of these supports are or can be funded by governmentally-financed programs. While we hope that in the future more employers will provide assistance to people with developmental disabilities directly (indeed, some already are), it is the case that many of the costs associated with "reasonable accommodation" are already paid for, or could be paid for, under other programs. The challenge to advocates is to both identify and further develop these technologies and supports and to ensure that they are available to people with developmental disabilities, their (potential) employers, and communities. The result will be that when discussions arise regarding who is "qualified" or what constitutes "reasonable accommodation," people with developmental disabilities, their families, and other advocates can make it easy for others to say *Yes*.

Staff members of the Administration on Developmental Disabilities (ADD) are continually seeking ways to increase the independence, productivity, and community inclusion of people with developmental disabilities. They see in the ADA an opportunity to create vastly improved futures for the people they serve. ADD has invested resources in making the promise of the ADA a reality for people with developmental disabilities across America through innovative projects funded by the Developmental Disabilities Councils in every state, through the pioneering work of the Uni-

versity Affiliated Programs in discovering better forms of accommodation, and through the efforts of the Protection and Advocacy Systems to promote and safeguard the rights of persons with developmental disabilities.

It is our belief that this vital work must continue. We trust that those who have fought for so long to see people with developmental disabilities treated with respect in the light of equality will persevere along with us. Together, we will continue to discover creative ways to ensure that every man, woman, and child with a developmental disability in American will be able, in the President's words, "to pass through once-closed doors into a bright new era of equality, independence and freedom."

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Appendix E

Section 504 Fact Sheet

What is it?

Section 504 is a section of the Rehabilitation Act of 1973 which protects the rights of persons with disabilities. It prohibits agencies or organization which receive federal funds from discriminating against otherwise qualified individuals solely on the basis of disability.

What is a disability under 504?

An individual is determined to have a disability if she/he:

- 1 Has a physical or mental impairment which substantially limits one or more major life activities (walking, seeing, hearing, speaking, breathing, learning, working, caring for oneself, performing manual tasks);
- 2 has a record of such impairment; *or*
- 3 is regarded as having such an impairment.

This can mean that a school-age child who has an attention deficit disorder and does not qualify for special education services may still be entitled to accommodation in regular education under Section 504.

What are "reasonable accommodations" under 504?

Accommodations must achieve meaningful equal opportunity, must consider the functional limitations of the person and alternative methods of performance. Some examples could be the following: modified testing, preferential seating, taped textbooks, readers, tailoring homework assignments, etc.

Are evaluations and IEP required?

A district must evaluate "any person who, because of handicap, needs or is believed to need special education or related services". Evaluation is also required prior to a significant change in placement.

A written plan describing placement and services must be developed. A formal IEP is not required, but decisions will be made by a group of persons. Placement decisions must be based on information from varied sources and must be documented. All information must be considered. Decisions must be made by a group of persons who are knowledgeable about the child, the meaning of the data, and placement options.

What are the responsibilities of schools?

Schools must provide assurance of non-discrimination, designate an employee to ensure compliance, provide grievance proce-

dures, identify and locate all qualified children with disabilities who are receiving public education, provide notice of district's 504 responsibilities and procedural safeguards. The procedural safeguards are as follows:

- 1 The right to written notice
- 2 The right to review records
- 3 The right to an impartial hearing

What if there appears to be a violation?

The Office of Civil Rights investigates Section 504 complaints. Minnesota is in Region V, 300 Wacker Drive, Chicago, Illinois 60606; telephone 312/353-2520.

Appendix F

Delegation & Nursing Practice

By Mary Tyrrell, Assistant Director,
Nursing Assistant Program, Minnesota Board of Nursing

The primary responsibility of the Minnesota Board of Nursing is to protect the public health, safety, and welfare through the regulation of nursing practice. Registered nurses and licensed practical nurses in Minnesota are granted licenses to practice nursing in Minnesota under the provisions of the Nurse Practice Act. This act establishes the parameters of practice within nursing. The professional nurse is authorized to delegate independent nursing functions and delegated medical functions to other nursing personnel. The licensed practical nurse is not given this authorization in the Nurse Practice Act.

Familiarity with delegation is especially important for the professional nurse in long term care who delegates a variety of tasks to the licensed practical nurse and the nursing assistant. Even if the assistant has a special title such as trained medication aide (TMA), home health aide (HHA), personal care assistant (PCA), or human services technician (HST), the decision to delegate nursing care rests with the registered nurse. The delegating nurse retains accountability for the act delegated to another person and has the responsibility to determine that the delegatee is competent to perform the delegated act. Furthermore, the delegating nurse must provide appropriate supervision.

The decision of whether or not to delegate to other nursing personnel rests with the professional nurse. Both the status of the resident or client and the knowledge and skill of the person receiving the delegation (the "delegatee") must be considered. Thus, the delegator has the responsibility to make a proper act of delegation by giving clear, specific directions to a person who can perform them safely and competently. And the delegatee has the responsibility of carrying out the delegated act or function correctly. Good communication between the giver and recipient is necessary so that any ambiguity in instruction or lack of ability can be addressed.

For example, the charge nurse in a facility may recognize that TMA appears overwhelmed with a work assignment. The TMA may be willing to take on the task, but it is the nurse's responsibility to verify that the work will be done safely. If the TMA makes a mistake, the nurse is responsible for the TMA's performance and is responsible for delegating properly.

Long-term care is an essential and creative component in

today's continuum of health care. The availability of staff is a critical issue, and delegation can be very cost-effective. However, safety of the client/resident must remain the primary issue.

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Appendix G

The Minnesota Nurse Practice Act

Chapter 148 – Public Health Occupations, Licensing Registered Nurses and Licensed Practical Nurses

148.171 – Definitions

Sections 148.171 to 148.285 shall be referred to as the Minnesota nurse practice act. As used in sections 148.171 to 148.285:

- 1 "Board" means the Minnesota board of nursing.
- 2 "Registered nurse," abbreviated R.N., means an individual licensed by the board to practice professional nursing.
- 3 The practice of professional nursing means the performance for compensation or personal profit of the professional interpersonal service of: a) providing a nursing assessment of the actual or potential health needs of individuals, families, or communities; b) providing nursing care supportive to or restorative of life by functions such as skilled ministrations of nursing care, supervising and teaching nursing personnel, health teaching and counseling, case finding, and referral to other health resources; and c) evaluating these actions.

The practice of professional nursing includes both independent nursing functions and delegated medical functions which may be performed in collaboration with other health team members, or may be delegated by the professional nurse to other nursing personnel. Independent nursing function may also be performed autonomously. The practice of professional nursing requires that level of special education, knowledge, and skill ordinarily expected of an individual who has completed an approved professional nursing education program as described in section 148.211, subdivision 1.

- 4 "Licensed practical nurse," abbreviated L.P.N., means an individual licensed by the board to practice practical nursing.
- 5 The practice of practical nursing means the performance for compensation or personal profit of any of those services in observing and caring for the ill, injured, or infirm, in applying counsel and procedure to safeguard life and health, in administering medication and treatment prescribed by a licensed health professional, which are commonly performed by licensed practical nurses and which require specialized knowledge and skill such as are taught or acquired in an approved school of practical nursing, but which do not require the specialized education, knowledge, and skill of a registered nurse.

- 6 "Nurse" means registered nurse and licensed practical nurse unless the context clearly refers to only one category.
- 7 "Nursing assistant" means an individual providing nursing or nursing-related services that do not require the specialized knowledge and skill of a nurse, at the direction of a nurse, but does not include a licensed health professional or an individual who volunteers to provide such services without monetary compensation.
- 8 "Public health nurse" means a registered nurse who meets the voluntary registration requirements established by rule.

HIST: 1945 c 242 s 1; 1955 c 34 s 1; 1959 c 140 s 1; 1974 c 554 s 1; 1988 c 440 s 1; 1989 c 194 s 3; 1990 c 483 s 1

148.181 Board of Nursing Membership; Vacancies; Disclosure

Subd. 1 – Membership: The board of nursing consists of sixteen members appointed by the governor, each of whom must be a resident of this state. Eight members must be registered nurses, each of whom must have graduated from an approved school of nursing, must be licensed and currently registered as a registered nurse in this state, and must have had at least five years experience in nursing practice, nursing administration, or nursing education immediately preceding appointment. One of the eight must have had at least two years executive or teaching experience in a baccalaureate degree nursing program approved by the board under section 148.251 during the five years immediately preceding appointment, one of the eight must have had at least two years executive or teaching experience in an associate degree nursing program approved by the board under section 148.251 during the five years immediately preceding appointment, one of the eight must be practicing professional nursing in a nursing home at the time of appointment, one of the eight must have had at least two years executive or teaching experience in a practical nursing program approved by the board under section 148.251 during the five years immediately preceding appointment, and one of the eight must have national certification as a registered nurse anesthetist, nurse practitioner, nurse midwife, or clinical nurse specialist. Four of the eight must have had at least five years of experience in nursing practice or nursing administration immediately preceding appointment. Four members must be licensed practical nurses, each of whom must have graduated from an approved school of nursing, must be licensed and currently registered as a licensed practical nurse in this state, and must have had at least five years experience in nursing practice immediately preceding appointment. The remaining four members must be public members as defined by section 214.02.

A member may be reappointed but may not serve more than two full terms consecutively. The governor shall attempt to make

appointments to the board that reflect the geography of the state. Board members who are nurses should reflect the broad mix of practice types and sites of nurses practicing in Minnesota.

Membership terms, compensation of members, removal of members, the filling of membership vacancies, and fiscal year and reporting requirements are as provided in sections 214.07 to 214.09. Any nurse on the board who during incumbency permanently ceases to be actively engaged in the practice of nursing or otherwise becomes disqualified for board membership is automatically removed, and the governor shall fill the vacancy. The provision of staff, administrative services, and office space; the review and processing of complaints; the setting of board fees; and other provisions relating to board operations are as provided in sections 148.171 to 148.285 and chapter 214. Each member of the board shall file with the secretary of state the constitutional oath of office before beginning the term of office.

Subd. 2 – Vacancies: On expiration of the term of a member who is a registered nurse, the governor may appoint a registered nurse from a list of members submitted by professional nursing groups. Likewise on expiration of the term of a member who is a licensed practical nurse, the governor may appoint a licensed practical nurse from a list of members submitted by licensed practical nursing groups. These lists should contain names of persons in number at least twice the number of places to be filled. Vacancies occurring on the board, when the member is a registered nurse or a licensed practical nurse, may be filled for the unexpired terms by appointments to be made by the governor from nominations submitted by nursing groups in the manner aforesaid or from other recommendations. Members shall hold office until a successor is appointed and qualified.

Subd. 3: Repealed, 1975 c 136 s 77

Subd. 3 – Disclosure: A disciplinary hearing must be closed to the public. Upon application of a party in a proceeding before the board under section 148.261, the board shall produce and permit the inspection and copying, by or on behalf of the moving party, of any designated documents or papers relevant to the proceedings, in accordance with rule 34 of the Minnesota rules of civil procedure.

HIST: 1945 c 242 s 2; 1955 c 34 638 s 14; 1975 c 136 s 10; 1975 c 360 s 1,2; 1976 c 222 s 50; 1976 c 239 s 55; 1981 c 94 s 1; 1986 c 444; 1989 c 194 s 4; 1993 c 88 s 1,2; 1993 c 105 s 1; 1993 c 366 s 1

148.191 Officers; Staff; Powers

Subd. 1 – Officers; Staff: The board shall elect from its members a president, a vice-president, and a secretary-treasurer who shall each serve for one year or until a successor is elected and qualifies. The board shall appoint and employ an executive director and may employ such persons as may be necessary to carry on its work. A majority of the board, including one officer, shall constitute a quorum at any meeting.

Subd. 2 – Powers:

A The board is authorized to adopt and, from time to time, revise rules not inconsistent with the law, as may be necessary to enable it to carry into effect the provisions of sections 148.171 to 148.285. The board shall prescribe by rule curricula and standards for schools and courses preparing persons for licensure under sections 148.171 to 148.285. It shall conduct or provide for surveys of such schools and courses at such times as it may deem necessary. It shall approve such schools and courses as meet the requirements of sections 148.171 to 148.285 and board rules. It shall examine, license, and renew the license of duly qualified applicants. It shall hold examinations at least once in each year at such time and place as it may determine. It shall by rule adopt, evaluate, and periodically revise, as necessary, requirements for licensure and for registration and renewal of registration as defined in section 148.231. It shall cause the prosecution of all persons violating sections 148.171 to 148.285 and have power to incur such necessary expense therefor. It shall register public health nurses who meet educational and other requirements established by the board by rule, including payment of a fee. Prior to the adoption of rules, the board shall use the same procedures used by the department of health to certify public health nurses. It shall have power to issue subpoenas, and to compel the attendance of witnesses and the production of all necessary documents and other evidentiary material. Any board member may administer oaths to witnesses, or take their affirmation. It shall keep a record of all its proceedings.

B The board shall have access to hospital, nursing home, and other medical records of a patient cared for by a nurse under review. If the board does not have a written consent from a patient permitting access to the patient's records, the nurse or facility shall delete any data in the record that identifies the patient before providing it to the board. The board shall have access to such other records as reasonably requested by the board to assist the board in its investigation. Nothing herein may be construed to allow access to any records protected by section 145.64. The board shall maintain any records obtained pursuant to this paragraph as investigative data under chapter 13.

Subd. 3: Repealed, 1989 c 194 s 22

HIST: 1945 c 242 s 3; 1955 c 847 s 13; 1975 c 136 s 12; 1975 c 240 s 1; 1975 c 360 s 3; 1976 c 222 s 51; 1983 c 260 s 36; 1986 c 444; 1989 c 194 s 5

148.211 – Licensing

Subd. 1 – Licensure by Examination: An applicant for a license to practice as a registered nurse or licensed practical nurse shall apply to the board for a license by examination on forms prescribed by the board and pay a fee in an amount determined by rule. An applicant applying for reexamination shall pay a fee in an amount determined by rule. In no case may fees be refunded.

Before being scheduled for examination, the applicant shall provide written evidence verified by oath that the applicant 1) has not engaged in conduct warranting disciplinary action as set forth in section 148.261; 2) meets secondary education requirements as determined by the board and other preliminary qualification requirements the board may prescribe by rule; and 3) has completed a course of study in a nursing program approved by the board, another United States nursing board, or a Canadian province. An applicant who graduates from a nursing program in another country, except Canada, must also successfully complete the Commission on Graduates of Foreign Nursing Schools Qualifying Examination. The nursing program must be approved for the preparation of applicants for the type of license for which the application has been submitted.

The applicant must pass a written examination in the subjects the board may determine. Written examination includes both paper and pencil examinations and examinations administered with a computer and related technology. Each written examination may be supplemented by an oral or practical examination. An applicant failing to pass the examination may apply for reexamination.

Upon submission by the applicant of an affidavit of graduation or transcript from an approved nursing program as well as proof that the applicant has passed the examination, paid the required fees, and met all other requirements stated in this subdivision, the board shall issue a license to the applicant. The board may issue a license with conditions and limitations if it considers it necessary to protect the public.

Subd. 2 – Licensure by Endorsement: The board shall issue a license to practice professional nursing or practical nursing without examination to an applicant who has been duly licensed or registered as a nurse under the laws of another state, territory, or country, if in the opinion of the board the applicant has the qualifications equivalent to the qualifications required in this state as stated in subdivision 1, all other laws not inconsistent with this section, and rules promulgated by the board.

Subd. 3: Repealed, 1976 c 222 s 209

Subd. 4 – Education Waived: A person who has been licensed as a licensed practical nurse in another state, who has passed a licensing examination acceptable to the board, and who has had 24 months of experience as a licensed practical nurse in the five years prior to applying for a license is not required to meet any additional educational requirements.

Subd. 5 – Denial of License: Refusal of an applicant to supply information necessary to determine the applicant's qualifications, failure to demonstrate qualifications, or failure to satisfy the requirements for a license contained in this section or rules of the board may result in denial of a license. The burden of proof is upon the applicant to demonstrate the qualifications and satisfac-

tion of the requirements.

HIST: 1945 c 242 s 5; 1955 c 34 s 4; 1961 c 56 s 1; 1967 c 68 s 1; 1969 c 53 s 1; 1975 c 360 s 4,5; 1976 c 222 s 52,53; 1981 c 94 s 2; 1986 c 444; 1989 c 194 s 6; 1993 c 88 s 3

148.212 – Temporary Permit

Upon receipt of the applicable licensure or re-registration fee and permit fee, and in accordance with rules of the board, the board may issue a nonrenewable temporary permit to practice professional or practical nursing to an applicant for licensure or reregistration who is not the subject of a pending investigation or disciplinary action, nor disqualified for any other reason, under the following circumstances:

- A The applicant for licensure by examination under section 148.211, subdivision 1, has graduated from an approved nursing program within the sixty days preceding board receipt of an affidavit of graduation or transcript and has been authorized by the board to write the licensure examination for the first time in the United States. The permit holder must practice professional or practical nursing under the direct supervision of a registered nurse. The permit is valid from the date of issue until the date the board takes action on the application or for sixty days, whichever occurs first.
- B The applicant for licensure by endorsement under section 148.211, subdivision 2, is currently licensed to practice professional or practical nursing in another state, territory, or Canadian province. The permit is valid from submission of a proper request until the date of board action on the application.
- C The applicant for licensure by endorsement under section 148.211, subdivision 2, or for reregistration under section 148.231, subdivision 5, is currently registered in a formal, structured refresher course or its equivalent for nurses that includes clinical practice.

HIST: 1989 c 194 s 7; 1993 c 88 s 4

148.231 – Registration; Failure to Register; Re-registration; Verification

Subd. 1 – Registration: Every person licensed to practice professional or practical nursing must maintain with the board a current registration for practice as a registered nurse or licensed practical nurse which must be renewed at regular intervals established by the board by rule. No certificate of registration shall be issued by the board to a nurse until the nurse has submitted satisfactory evidence of compliance with the procedures and minimum requirements established by the board.

The fee for periodic registration for practice as a nurse shall be determined by the board by rule. A penalty fee shall be added for any application received after the required date as specified by

the board by rule. Upon receipt of the application and the required fees, the board shall verify the application and the evidence of completion of continuing education requirements in effect, and thereupon issue to the nurse a certificate of registration for the next renewal period.

Subd. 2: Repealed, 1981 c 94 s 12

Subd. 3: Repealed, 1976 c 222 s 209

Subd. 4 – Failure to Register: Any person licensed under the provisions of sections 148.171 to 148.285 who fails to register within the required period shall not be entitled to practice nursing in this state as a registered nurse or licensed practical nurse.

Subd. 5 – Re-registration: A person whose registration has lapsed desiring to resume practice shall make application for re-registration, submit satisfactory evidence of compliance with the procedures and requirements established by the board, and pay the registration fee for the current period to the board. Thereupon, the registration certificate shall be issued to the person who shall immediately be placed on the practicing list as a registered nurse or licensed practical nurse.

Subd. 6 – Verification: A person licensed under the provisions of sections 148.171 to 148.285 who requests the board to verify a Minnesota license to another state, territory, or country or to an agency, facility, school, or institution shall pay a fee to the board for each verification.

HIST: 1945 c 242 s 7; 1947 c 286 s 1; 1955 c 34 s 5; 1961 c 8 s 2; 1967 c 68 s 2; 1969 c 53 s 2,3; 1971 c 131 s 1; 1975 c 240 s 2; 1975 c 360 s 6,7; 1976 c 149 s 30; 1981 c 94 s 3-6; 1986 c 444; 1999 c 194 s 8

148.232 – Registration of Public Health Nurses.

A public health nurse certified for public health duties by the commissioner of health under section 145A.06, subdivision 3, or previous authority must be deemed to be registered as a public health nurse under the provisions of sections 148.171 to 148.285.
HIST: 1989 c 194 s 9

148.235 – Prescribing Drugs and Therapeutic Devices.

Subd. 1 – Nurse-midwives: A registered nurse who has graduated from a program of study designed to prepare registered nurses for advanced practice as nurse-midwives and who is certified through the national professional nursing organization for nurse-midwives may prescribe and administer drugs and therapeutic devices within practice as a nurse-midwife.

Subd. 2 – Nurse Practitioners: A registered nurse who 1) has graduated from a program of study designed to prepare registered nurses for advanced practice as nurse practitioners; 2) is certified through a national professional nursing organization which certifies nurse practitioners and is included in the list of professional nursing organizations adopted by the board under section 62A.15, subdivision 3a; and 3) has a written agreement with a physician

based on standards established by the Minnesota nurses association and the Minnesota medical association that defines the delegated responsibilities related to the prescription of drugs and therapeutic devices, may prescribe and administer drugs and therapeutic devices within the scope of the written agreement and within practice as a nurse practitioner.

Subd. 3 – Dispensing Authority: An advanced practice nurse who is authorized under this section to prescribe drugs is authorized to dispense drugs subject to the same requirements established for the prescribing of drugs. This authority to dispense extends only to those drugs described in the written agreement entered into under this section. The authority to dispense includes, but is not limited to, the authority to receive and dispense sample drugs.

Subd. 4 – Clinical Specialists in Psychiatric and Mental Health Nursing: A registered nurse who 1) has a masters degree; 2) is certified through a national professional nursing organization which certifies clinical specialists in psychiatric and mental health nursing and is included in the list of professional nursing organizations adopted by the board under section 62A.15, subdivision 3a; 3) has successfully completed no less than thirty hours of formal study in the prescribing of psychotropic medications and medications to treat their side effects which included instruction in health assessment, psychotropic classifications, psychopharmacology, indications, dosages, contraindications, side effects, and evidence of application; and 4) has a written agreement with a psychiatrist based on standards established by the Minnesota nurses association and the Minnesota psychiatric association that specifies and defines the delegated responsibilities related to the prescription of drugs in relationship to the diagnosis, may prescribe and administer drugs used to treat psychiatric and behavioral disorders and the side effects of those drugs within the scope of the written agreement and within practice as a clinical specialist in psychiatric and mental health nursing.

Nothing in this subdivision removes or limits the legal professional liability of the treating psychiatrist, clinical nurse specialist, mental health clinic, or hospital for the prescription and administration of drugs by a clinical specialist in accordance with this subdivision.

Subd. 5 – Rules

A The board shall promulgate rules to provide for the following:

- 1 A system of identifying advanced practice nurses eligible to prescribe drugs as authorized under this section;
- 2 A system of transmitting to pharmacists the identity of advanced practice nurses eligible to prescribe drugs; *and*
- 3 A fee to nurse practitioners and certified clinical specialists in psychiatric and mental health nursing who seek prescribing authority.

B The repeal of subdivision 2, paragraph (b), does not automatically repeal rules adopted under that paragraph.

HIST: 1990 c 483 s 2; 1993 c 337 s 10; 1994 c 389 s 2; 1994 c 470 s 1-3

148.236 – Funding for Nursing Grants

Subd. 1 – Registered Nurse Funding:

A The nursing grant program shall be funded by a \$5.50 fee on each registration renewal of registered nurses as provided under section 148.231, unless the applicant specifically indicates on the renewal form that the applicant does not wish to participate in the funding of this program. The board of nursing shall transfer all money received under this subdivision, less an amount sufficient to pay the costs of administering the program not to exceed twelve percent of the fee collected under this subdivision, to the higher education coordinating board on a quarterly basis. This money is available until expended by the higher education coordinating board. By January 1, 1991, and each subsequent year, the board of nursing shall provide an estimate to the higher education coordinating board of the amount of money that may be available each year based on the number of anticipated registration renewals in that year.

B Notwithstanding paragraph "A", up to the first \$11,000 of fees collected under this subdivision may be used to program the board of nursing's computer system for purposes of administering this section.

Subd. 2 – Licensed Practical Nurse Funding:

A The nursing grant program shall be funded by a \$5.50 fee on each registration renewal of licensed practical nurses as provided under section 148.231, unless the applicant specifically indicates on the renewal form that the applicant does not wish to participate in the funding of this program. The board of nursing shall transfer all money received under this subdivision, less an amount sufficient to pay the costs of administering the program not to exceed twelve percent of the fee collected under this subdivision, to the higher education coordinating board on a quarterly basis. This money is available until expended by the higher education coordinating board. By January 1, 1991, and each subsequent year, the board of nursing shall provide an estimate to the higher education coordinating board of the amount of money that may be available each year based on the number of anticipated registration renewals in that year.

B Notwithstanding paragraph "A", up to the first \$6,000 of fees collected under this subdivision may be used to program the board of nursing's computer system for purposes of administering this section.

HIST: 1990 c 568 art 2 s 100

148.241 – Expenses

Subd. 1 – Appropriation: The expenses of administering sections

148.171 to 148.285 shall be paid from the appropriation made to the Minnesota board of nursing.

Subd. 2 – Expenditure: All amounts appropriated to the board shall be held subject to the order of the board to be used only for the purpose of meeting necessary expenses incurred in the performance of the purposes of sections 148.171 to 148.285, and the duties imposed thereby as well as the promotion of nursing education and standards of nursing care in this state.

HIST: 1945 c 242 s 8; 1955 c 34 s 3; 1973 c 638 s 16; 1976 c 222 s 54; 1989 c 194 s 10

148.251 – Nursing Program

Subd. 1 – Initial Approval: An institution desiring to conduct a nursing program shall apply to the board and submit evidence that:

- 1 It is prepared to provide a program of theory and practice in professional or practical nursing that meets the program approval standards adopted by the board. Instruction and required experience may be obtained in one or more institutions or agencies outside the applying institution as long as the nursing program retains accountability for all clinical and nonclinical teaching.
- 2 It is prepared to meet other standards established by law and by the board.

Subd. 2: Repealed, 1989 c 194 s 22

Subd. 3 – Continuing Approval: From time to time as deemed necessary by the board, it shall be the duty of the board, through its representatives, to survey all nursing programs in the state. If the results of the survey show that a nursing program meets all board rules, the board shall continue approval of the nursing program.

Subd. 4 – Loss of Approval: If the board determines that an approved nursing program is not maintaining the standards required by the statutes and board rules, notice thereof in writing specifying the defect shall be given to the program. If a program fails to correct these conditions to the satisfaction of the board within a reasonable time, approval of the program shall be revoked and the program shall be removed from the list of approved nursing programs.

Subd. 5 – Reinstatement of Approval: The board shall reinstate approval of a nursing program upon submission of satisfactory evidence that its program of theory and practice meets the standards required by statutes and board rules.

Subd. 6 – Advanced Standing: Associate degree nursing programs approved or seeking to be approved by the board shall provide for advanced standing for licensed practical nurses in recognition of their nursing education and experience.

HIST: 1945 c 242 s 9; 1961 c 56 s 2; 1975 c 360 s 8; 1981 c 94 s 7; 1989 c 194 s 11

148.261 – Grounds for Disciplinary Action

Subd. 1 – Grounds Listed: The board may deny, revoke, suspend, limit, or condition the license and registration of any person to practice professional or practical nursing under sections 148.171 to 148.285, or to otherwise discipline a licensee or applicant as described in section 148.262. The following are grounds for disciplinary action:

- 1 Failure to demonstrate the qualifications or satisfy the requirements for a license contained in sections 148.171 to 148.285 or rules of the board. In the case of a person applying for a license, the burden of proof is upon the applicant to demonstrate the qualifications or satisfaction of the requirements.
- 2 Employing fraud or deceit in procuring or attempting procure a permit, license, or registration certificate to practice professional or practical nursing or attempting to subvert the licensing examination process. Conduct that subverts or attempts to subvert the licensing examination process includes, but is not limited to:
 - i conduct that violates the security of the examination materials, such as removing examination materials from the examination room or having unauthorized possession of any portion of a future, current, or previously administered licensing examination;
 - ii conduct that violates the standard of test administration, such as communicating with another examinee during administration of the examination, copying another examinee's answers, permitting another examinee to copy one's answers, or possessing unauthorized materials; or
 - iii impersonating an examinee or permitting an impersonator to take the examination on one's own behalf.
- 3 Conviction during the previous five years of a felony or gross misdemeanor reasonably related to the practice of professional or practical nursing. Conviction as used in this subdivision includes a conviction of an offense that if committed in this state would be considered a felony or gross misdemeanor without regard to its designation elsewhere, or a criminal proceeding where a finding or verdict of guilt is made or returned but the adjudication of guilt is either withheld or not entered.
- 4 Revocation, suspension, limitation, conditioning, or other disciplinary action against the person's professional or practical nursing license in another state, territory, or country; failure to report to the board that charges regarding the person's nursing license are pending in another state, territory, or country; or having been refused a license by another state, territory, or country.
- 5 Failure to or inability to perform professional or practical

nursing as defined in section 148.171, paragraph "3" or "5", with reasonable skill and safety, including failure of a registered nurse to supervise or a licensed practical nurse to monitor adequately the performance of acts by any person working at the nurse's direction.

- 6 Engaging in unprofessional conduct, including, but not limited to, a departure from or failure to conform to board rules of professional or practical nursing practice that interpret the statutory definition of professional or practical nursing as well as provide criteria for violations of the statutes, or, if no rule exists, to the minimal standards of acceptable and prevailing professional or practical nursing practice, or any nursing practice that may create unnecessary danger to a patient's life, health, or safety. Actual injury a patient need not be established under this clause.
- 7 Delegating or accepting the delegation of a nursing function or a prescribed health care function when the delegation or acceptance could reasonably be expected to result in unsafe or ineffective patient care.
- 8 Actual or potential inability to practice nursing with reasonable skill and safety to patients by reason of illness, use of alcohol, drugs, chemicals, or any other material, or as a result of any mental or physical condition.
- 9 Adjudication as mentally incompetent, mentally ill, a chemically dependent person, or a person dangerous to the public by a court of competent jurisdiction, within or without this state.
- 10 Engaging in any unethical conduct, including, but not limited to, conduct likely to deceive, defraud, or harm the public, or demonstrating a willful or careless disregard for the health, welfare, or safety of a patient. Actual injury need not be established under this clause.
- 11 Engaging in conduct with a patient that is sexual or may reasonably be interpreted by the patient as sexual, or in any verbal behavior that is seductive or sexually demeaning to a patient, or engaging in sexual exploitation of a patient or former patient.
- 12 Obtaining money, property, or services from a patient, other than reasonable fees for services provided to the patient, through the use of undue influence, harassment, duress, deception, or fraud.
- 13 Revealing a privileged communication from or relating to a patient except when otherwise required or permitted by law.
- 14 Engaging in abusive or fraudulent billing practices, including violations of federal Medicare and Medicaid laws or state medical assistance laws.

- 15 Improper management of patient records, including failure to maintain adequate patient records, to comply with a patient's request made pursuant to section 144.335, or to furnish a patient record or report required by law.
- 16 Knowingly aiding, assisting, advising, or allowing an unlicensed person to engage in the unlawful practice of professional or practical nursing.
- 17 Violating a rule adopted by the board, an order of the board, or a state or federal law relating to the practice of professional or practical nursing, or a state or federal narcotics or controlled substance law.
- 18 Knowingly providing false or misleading information that is directly related to the care of that patient unless done for an accepted therapeutic purpose such as the administration of a placebo.
- 19 Aiding suicide or aiding attempted suicide in violation of section 609.215 as established by any of the following:
 - i a copy of the record of criminal conviction or plea of guilty for a felony in violation of section 609.215, subdivision 1 or 2;
 - ii a copy of the record of a judgment of contempt of court for violating an injunction issued under section 609.215, subd. 4;
 - iii a copy of the record of a judgment assessing damages under section 609.215, subdivision 5; *or*
 - iv a finding by the board that the person violated section 609.215, subdivision 1 or 2. The board shall investigate any complaint of a violation of section 609.215, subdivision 1 or 2.
- 20 Practicing outside the scope of practice authorized by section 148.171, paragraph "3" or "5".
- 21 Making a false statement or knowingly providing false information to the board, failing to make reports as required by section 148.263, or failing to cooperate with an investigation of the board as required by section 148.265.
- 22 Engaging in false, fraudulent, deceptive, or misleading advertising.

Subd. 2: Repealed, 1976 c 222 s 209

Subd. 3: Repealed, 1989 c 194 s 22

Subd. 4 – Evidence: In disciplinary actions alleging a violation of subdivision 1, clause "3" or "4", a copy of the judgment or proceeding under the seal of the court administrator or of the administrative agency that entered the same shall be admissible into evidence without further authentication and shall constitute prima facie evidence of the violation concerned.

Subd. 5 – Examination; Access to Medical Data: The board may take the following actions if it has probable cause to believe that grounds for disciplinary action exist under subdivision 1, clause "8" or "9":

A It may direct the applicant or nurse to submit to a mental or physical examination or chemical dependency evaluation. For the purpose of this subdivision, when a nurse licensed under sections 148.171 to 148.285 is directed in writing by the board to submit to a mental or physical examination or chemical dependency evaluation, that person is considered to have consented and to have waived all objections to admissibility on the grounds of privilege. Failure of the applicant or nurse to submit to an examination when directed constitutes an admission of the allegations against the applicant or nurse, unless the failure was due to circumstances beyond the person's control, and the board may enter a default and final order without taking testimony or allowing evidence to be presented. A nurse affected under this paragraph shall, at reasonable intervals, be given an opportunity to demonstrate that the competent practice of professional or practical nursing can be resumed with reasonable skill and safety to patients. Neither the record of proceedings nor the orders entered by the board in a proceeding under this paragraph, may be used against a nurse in any other proceeding.

B It may, notwithstanding sections 13.42, 144.651, 595.02, or any other law limiting access to medical or other health data, obtain medical data and health records relating to a registered nurse, licensed practical nurse, or applicant for a license without that person's consent. The medical data may be requested from a provider, as defined in section 144.335, subdivision 1, paragraph (b), an insurance company, or a government agency, including the department of human services. A provider, insurance company, or government agency shall comply with any written request of the board under this subdivision and is not liable in any action for damages for releasing the data requested by the board if the data are released pursuant to a written request under this subdivision unless the information is false and the provider giving the information knew, or had reason to believe, the information was false. Information obtained under this subdivision is classified as private data on individuals as defined in section 13.02.

HIST: 1945 c 242 s 10; 1975 c 360 s 9; 1976 c 222 s 55; 1986 c 444; 1989 c 194 s 12; 1992 c 464 art 1 s 56; 1992 c 559 art 1 s 4; 1992 c 577 s 3; 1993 c 88 s 5

148.262 – Forms of Disciplinary Action; Automatic Suspension; Temporary Suspension; Reissuance

Subd. 1 – Forms of Disciplinary Action: When the board finds that grounds for disciplinary action exist under section 148.261, subdivision 1, it may take one or more of the following actions:

- 1 Deny the license, registration, or registration renewal;
- 2 Revoke the license;
- 3 Suspend the license;
- 4 Impose limitations on the nurse's practice of professional or prac-

tical nursing including, but not limited to, limitation of scope of practice or the requirement of practice under supervision;

- 5 Impose conditions on the retention of the license including, but not limited to, the imposition of retraining or rehabilitation requirements or the conditioning of continued practice on demonstration of knowledge or skills by appropriate examination, monitoring, or other review;
- 6 Impose a civil penalty not exceeding \$10,000 for each separate violation, the amount of the civil penalty to be fixed as to deprive the nurse of any economic advantage gained by reason of the violation charged, to reimburse the board for the cost of counsel, investigation, and proceeding, and to discourage repeated violations;
- 7 Order the nurse to provide unremunerated service;
- 8 Censure or reprimand the nurse; or
- 9 Any other action justified by the facts in the case.

Subd. 2 – Automatic Suspension: Unless the board orders otherwise, a license to practice professional or practical nursing is automatically suspended if:

- 1 A guardian of a nurse is appointed by order of a court under sections 525.54 to 525.61;
- 2 The nurse is committed by order of a court under chapter 253b; *or*
- 3 The nurse is determined to be mentally incompetent, mentally ill, chemically dependent, or a person dangerous to the public by a court of competent jurisdiction within or without this state.

The license remains suspended until the nurse is restored to capacity by a court and, upon petition by the nurse, the suspension is terminated by the board after a hearing or upon agreement between the board and the nurse.

Subd. 3 – Temporary Suspension of License: In addition to any other remedy provided by law, the board may, through its designated board member under section 214.10, subdivision 2, temporarily suspend the license of a nurse without a hearing if the board finds that there is probable cause to believe the nurse has violated a statute or rule the board is empowered to enforce and continued practice by the nurse would create a serious risk of harm to others. The suspension shall take effect upon written notice to the nurse, served by first-class mail, specifying the statute or rule violated. The suspension shall remain in effect until the board issues a temporary stay of suspension or a final order in the matter after a hearing or upon agreement between the board and the nurse. At the time it issues the suspension notice, the board shall schedule a disciplinary hearing to be held under the administrative procedure act. The nurse shall be provided with at least twenty days' notice of any hearing held under this subdivision. The hearing

shall be scheduled to begin no later than thirty days after the issuance of the suspension order.

Subd. 4 – Reissuance: The board may reinstate and reissue a license or registration certificate to practice professional or practical nursing, but as a condition may impose any disciplinary or corrective measure that it might originally have imposed. Any person whose license or registration has been revoked, suspended, or limited may have the license reinstated and a new registration issued when, in the discretion of the board, the action is warranted, provided that the person shall be required by the board to pay the costs of the proceedings resulting in the revocation, suspension, or limitation of the license or registration certificate and reinstatement of the license or registration certificate, and to pay the fee for the current registration period. The cost of proceedings shall include, but not be limited to, the cost paid by the board to the office of administration hearings and the office of the attorney general for legal and investigative services, the costs of a court reporter and witnesses, reproduction of records, board staff time, travel, and expenses, and board members' per diem reimbursements, travel costs, and expenses.

HIST: 1989 c 194 s 13; 1Sp1994 c 1 art 2 s 8

148.263 – Reporting Obligations

Subd. 1 – Permission to Report: A person who has knowledge of any conduct constituting grounds for discipline under sections 148.171 to 148.285 may report the alleged violation to the board.

Subd. 2 – Institutions: The chief nursing executive or chief administrative officer of any hospital, clinic, prepaid medical plan, or other health care institution or organization located in this state shall report to the board any action taken by the institution or organization or any of its administrators or committees to revoke, suspend, limit, or condition a nurse's privilege to practice in the institution, or as part of the organization, any denial of privileges, any dismissal from employment, or any other disciplinary action. The institution or organization shall also report the resignation of any nurse before the conclusion of any disciplinary proceeding, or before commencement of formal charges, but after the nurse had knowledge that formal charges were contemplated or in preparation. The reporting described by this subdivision is required only if the action pertains to grounds for disciplinary action under section 148.261.

Subd. 3 – Licensed Professionals: A person licensed by a health-related licensing board as defined in section 214.01, subdivision 2, shall report to the board personal knowledge of any conduct the person reasonably believes constitutes grounds for disciplinary action under sections 148.171 to 148.285 by any nurse including conduct indicating that the nurse may be incompetent, may have engaged in unprofessional or unethical conduct, or may be mentally or physically unable to engage safely in the practice of profes-

sional or practical nursing.

Subd. 4 – Insurers: Four times each year, by the first day of February, May, August, and November, each insurer authorized to sell insurance described in section 60A.06, subdivision 1, clause 13, and providing professional liability insurance to registered nurses or licensed practical nurses shall submit to the board a report concerning any nurse against whom a malpractice award has been made or who has been a party to a settlement. The report must contain at least the following information:

- 1 The total number of settlements or awards;
- 2 The date settlement or award was made;
- 3 The allegations contained in the claim or complaint leading to the settlement or award;
- 4 The dollar amount of each malpractice settlement or award and whether that amount was paid as a result of a settlement or of an award; *and*
- 5 The name and address of the practice of the nurse against whom an award was made or with whom a settlement was made.

An insurer shall also report to the board any information it possesses that tends to substantiate a charge that a nurse may have engaged in conduct violating sections 148.171 to 148.285.

Subd. 5 – Courts: The court administrator of district court or another court of competent jurisdiction shall report to the board any judgment or other determination of the court that adjudges or includes a finding that a nurse is mentally ill, mentally incompetent, chemically dependent, a person dangerous to the public, guilty of a felony or gross misdemeanor, guilty of a violation of federal or state narcotics laws or controlled substances act, guilty of operating a motor vehicle while under the influence of alcohol or a controlled substance, or guilty of an abuse or fraud under Medicare or Medicaid, appoints a guardian of the nurse under sections 525.54 to 525.61, or commits a nurse under chapter 253B.

Subd. 6 – Deadlines; Forms: Reports required by subdivisions 2 to 5 must be submitted no later than thirty days after the occurrence of the reportable event or transaction. The board may provide forms for the submission of reports required by this section, may require that the reports be submitted on the forms provided, and may adopt rules necessary to assure prompt and accurate reporting. The board shall review all reports, including those submitted after the deadline.

HIST: 1989 c 194 s 14; ISpl994 c 1 art 2 s 9

148.264 – Immunity

Subd. 1 – Reporting: Any person, health care facility, business, or organization is immune from civil liability or criminal prosecution

for submitting in good faith a report to the board under section 148.263 or for otherwise reporting in good faith to the board violations or alleged violations of sections 148.171 to 148.285. All such reports are investigative data as defined in chapter 13.

Subd. 2 – Investigation: Members of the board and persons employed by the board or engaged in the investigation of violations and in the preparation and management of charges of violations of sections 148.171 to 148.285 on behalf of the board or persons participating in the investigation or testifying regarding charges of violations are immune from civil liability and criminal prosecution for any actions, transactions, or publications in the execution of, or relating to, their duties under sections 148.171 to 148.285.
HIST: 1989 c 194 s 15

148.265 – Nurse Cooperation

A nurse who is the subject of an investigation by or on behalf of the board shall cooperate fully with the investigation. Cooperation includes responding fully and promptly to any question raised by or on behalf of the board relating to the subject of the investigation and providing copies of patient or other records in the nurse's possession, as reasonably requested by the board, to assist the board in its investigation and to appear at conferences and hearings scheduled by the board. The board shall pay for copies requested. If the board does not have a written consent from a patient permitting access to the patient's records, the nurse shall delete any data in the record that identify the patient before providing it to the board. The board shall maintain any records obtained pursuant to this section as investigative data under chapter 13. The nurse shall not be excused from giving testimony or producing any documents, books, records, or correspondence on the grounds of self-incrimination, but the testimony or evidence may not be used against the nurse in any criminal case.

HIST: 1989 c 194 s 16

148.266 – Disciplinary Record on Judicial Review

Upon judicial review of any board disciplinary action taken under sections 148.171 to 148.285, the reviewing court shall seal the administrative record, except for the board's final decision, and shall not make the administrative record available to the public.

HIST: 1989 c 194 s 17

148.271 – Exemptions: The provisions of sections 148.171 to 148.285 shall not prohibit:

- 1 The furnishing of nursing assistance in an emergency.
- 2 The practice of professional or practical nursing by any legally qualified registered or licensed practical nurse of another state who is employed by the United States government or any bureau, division, or agency thereof while in the discharge of official duties.

- 3 The practice of any profession or occupation licensed by the state, other than professional or practical nursing, by any person duly licensed to practice the profession or occupation, or the performance by a person of any acts properly coming within the scope of the profession, occupation, or license.
- 4 The provision of a nursing or nursing-related service by a nursing assistant who has been delegated the specific function and is supervised by a registered nurse or monitored by a licensed practical nurse.
- 5 The care of the sick with or without compensation when done in a nursing home covered by the provisions of section 144A.09, subdivision 1.
- 6 Professional nursing practice by a registered nurse or practical nursing practice by a licensed practical nurse licensed in another state or territory who is in Minnesota as a student enrolled in a formal, structured course of study, such as a course leading to a higher degree, certification in a nursing specialty, or to enhance skills in a clin while the student is practicing in the course.
- 7 Professional or practical nursing practice by a student practicing under the supervision of an instructor while the student is enrolled in a nursing program approved by the board under section 148.251.

HIST: 256 s 1; 1981 c 94 s 8; 1986 c 444: 1989 c 194 s 18 1945 c 242 s 11; 1959 c 140 s 2; 1975 c 360 s 10; 1977 c

148.281 – Violations; Penalty

Subd. 1 – Violations Described: It shall be unlawful for any person, corporation, or association, to:

- 1 Sell or fraudulently obtain or furnish any nursing diploma, license, or record, or aid or abet therein;
- 2 Practice professional or practical nursing or practice as a public health nurse under cover of any diploma, permit, license, registration certificate, or record illegally or fraudulently obtained or signed or issued unlawfully or under fraudulent representation;
- 3 Practice professional or practical nursing unless the person has been issued a temporary permit under the provisions of section 148.212 or is duly licensed and currently registered to do so under the provisions of sections 148.171 to 148.285;
- 4 Use any abbreviation or other designation tending to imply licensure as a registered nurse or licensed practical nurse unless duly licensed and currently registered so to practice professional or practical nursing under the provisions of sections 148.171 to 148.285 except as authorized by the board by rule;
- 5 Use any abbreviation or other designation tending to imply

registration as a public health nurse unless duly registered by the board;

- 6 Practice professional or practical nursing in a manner prohibited by the board in any limitation of a license or registration issued under the provisions of sections 148.171 to 148.285;
- 7 Practice professional or practical nursing during the time a license or current registration issued under the provisions of sections 148.171 to 148.285 shall be suspended or revoked;
- 8 Conduct a nursing program for the education of persons to become registered nurses or licensed practical nurses unless the program has been approved by the board; and
- 9 Knowingly employ persons in the practice of professional or practical nursing who have not been issued a current permit, license, or registration certificate to practice as a nurse in this state.

Subd. 1a: Repealed, 1989 c 194 s 22

Subd. 2 – Penalty: Any person, corporation, or association violating any provisions of subdivision 1 shall be guilty of a gross misdemeanor, and shall be punished according to law.

HIST: 1945 c 242 s 12,13; 1959 c 140 s 4; 1975 c 360 s 11; 1977 c 256 s 2; 1986 c 444; 1989 c 194 s 19

148.283 – Unauthorized Practice of Professional and Practical Nursing

The practice of professional or practical nursing by any person who has not been licensed to practice professional or practical nursing under the provisions of sections 148.171 to 148.285, or whose license has been suspended or revoked, or whose registration has expired, is hereby declared to be inimical to the public health and welfare and to constitute a public nuisance. Upon complaint being made thereof by the board, or any prosecuting officer, and upon a proper showing of the facts, the district court of the county where such practice occurred may enjoin such acts and practice. Such injunction proceeding shall be in addition to, and not in lieu of, all other penalties and remedies provided by law.

HIST: 1959 c 140 s 6; 1989 c 194 s 20

148.285 – Transfer of Assets

All moneys, property, and property rights belonging to and under the control of the board of examiners, are hereby transferred and appropriated to the control and use of the board hereunder and the purpose provided herein.

HIST: 1945 c 242 s 14

Appendix H

Comparison of LSN & SHP Roles

LSN	SHP
Health Room Organization	
• Plans weekly schedule • Plans room arrangement • Plans activities for health program • Determines stock needed	• Implements plans as specified by LSN • Keeps room organized • Maintains inventory and orders supplies
Health Assessment	
• Assesses individual children	• Assists with monitoring, reporting, documenting
Individual Health Planning	
• Develops, implements, & assists in evaluating IEP	• Carries out plan to meet the child's health needs
Individual Educational Planning	
• Assesses individual children	• Carries out plan as appropriate
Health Counseling	
• Counsels based on the individual & group needs based on assessment	• Reinforces health concepts during individual student contact
Teaching	
• Provides info on resources • Teaches classes on request	• Orders resources on request • Types/duplicated materials
Behavior Management	
• Plans behavior mgt. strategies for students based on IEP or IHP	• Implements behavior mgt. strategies with same emphasis techniques as other staff
Working with Parents	
• Meets with parents • Initiates conferences on child's health	• Facilitates nurse-parent communication • Sends out memos; schedules meetings and conferences

Appendix I

Statement on the Nursing Activities of Unlicensed Persons

Purpose

The purpose of the National Council of State Boards of Nursing (NCSBN) in formulating this statement is to provide information to jurisdictions regarding the regulation of nursing acts performed by unlicensed persons.

Introduction

Unlicensed persons performing nursing acts has been a concern since the early 1900s. In the early 1900s the establishment of standards of nursing led to the formation of boards of nursing. Early licensing laws delineated the educational preparation required to become a nurse; however, they did not define nursing practice. Anyone who had successfully completed the requisite training program and examination was identified as a registered nurse.

Because nursing practice lacked definition, anyone could perform nursing functions as long as they did not identify themselves as nurses. However, the care that was provided then was custodial in nature because nursing care consisted of assisting with the activities of daily living. Because of the simplicity of nursing tasks in that time, it is not surprising that unlicensed persons learned on the job how to give custodial care.

Today, unlicensed persons are trained on the job or in short-term training programs and are employed to perform nursing acts or functions that range from custodial to complex. These ever-expanding job roles for unlicensed persons are of growing concern to the nursing and consumer communities. Some of the possible reasons for the increase of nursing acts being performed by unlicensed persons and the role of boards of nursing in this issue will be addressed.

Through the years, health care, including nursing, has become far more sophisticated. Nursing is no longer a compilation of tasks and caring related to daily living. The process of caring and doing in nursing are now integrated with technology. The integration of knowledge, judgment and skill is needed to practice nursing. As a result, the field of nursing has come to recognize the need for academic preparation for its practitioners.

The image of nursing commonly held by the public and many employers is that the intellectual component is not essential to the

practice of nursing. This misperception of nursing has not changed even as the complexity of client's problems and need for care has increased; thus, the job market within nursing of unlicensed persons has increased.

The 1960s and 1970s focused the nation's attention on improving the availability of health care for all. With the inauguration of Medicare and Medicaid programs and widespread availability of comprehensive health insurance, approximately ninety percent of all health care services were being reimbursed by third party payers by 1981. The public policy that promoted third party reimbursement added little incentive to health care providers to economize. As a result, within this time frame, the cost of health care tripled in the United States.

Other costly shifts took place in the health care system beginning in the 1970s. Public policy changes expanded or relocated services so that these evolved a demand for health care, especially nursing services, in a more settings than had ever been experienced. De-institutionalization caused many services to be shifted into the community. Also occurring in this period was an emphasis on health care as a right rather than a privilege. Changes in public policy promoting accessibility of care for all increased the public's expectation for care in many arenas and not just in the traditional physician's office, hospital, or nursing home.

There are many examples of how public policy made health care more widely accessible, often in previously underserved areas. Handicapped children who had previously been institutionalized or uneducated were mainstreamed into the public school classrooms, requiring schools to provide more complex health services. The chronically mentally handicapped were de-institutionalized and often needed community-based health services. Communities made strides in improving the quality and availability of emergency services which required increased manpower. In response to societal changes, prisons began to provide health care services to inmates, requiring staff who could provide these health services.

Related changes occurred even in the traditional facilities. Chronic care once provided in hospitals was shifted to long term care facilities or to home settings because more of the chronically ill were simply living for much longer periods of time and were requiring care during their expanded lifespans. The elderly population also rose with better standards of living and better health care. More nursing homes were built to care for the elderly and for those with chronic debilitating illnesses, while the need for care in people's private homes continued to grow as well. These examples reflect how more people came to expect broader services as a result of public policies.

Formerly, many of these services were unavailable or were available from nurses and those they supervised in institutions. Now community settings were responsible for providing health care which was mainly nursing care. This care was often needed on an

intermittent or part time basis and at low cost. Nurses simply were not available in sufficient numbers or were not hired because of cost. These forces resulted in unlicensed persons, who frequently lacked any institution or supervision by nurses, carrying out ever increasing complex care.

The use of unlicensed persons was also encouraged by many health care businesses. The possibility of making large profits through the expanded third party reimbursement mechanisms gave birth to many health care businesses. These businesses often chose to use unlicensed persons in order to keep profits high.

In the 1980s, the public policies that stimulated runaway growth in the health care industry came under criticism. Americans expected accessible, quality health care for all segments of the population, but were unable to afford the rising health care costs. In order to control escalating costs, the health care industry was coerced into implementing cost containment measures by the government, the industrial community, and the insurance industry.

With cost containment came greater increasing demand for home care delivery and even greater efforts from health care businesses to use unlicensed persons. Because nursing services are required on such an ongoing intensive basis, they are a substantial budgetary item. Thus the price of unlicensed staff members continues to be attractive.

Another justification used for employing unlicensed persons has been the current nursing shortage. This argument is weak because the impetus for unlicensed persons to be hired to perform nursing services has existed in times of abundant supply of nurses as well as in shortages. At this time there are nurses, especially LPNs, who are available in places where they are being bypassed in favor of unlicensed and unregulated persons.

Today one of the driving forces to hire unlicensed personnel is largely financial in nature. The one time concerns of the previous decades regarding accessibility and quality which brought runaway costs have now been controlled and the patterns of care is determined by the money available. Unlicensed persons remain an attractive substitute to employers who often hold the common misconceptions about nursing and who have serious financial concerns.

This inappropriate use of unlicensed persons to perform nursing act at a lesser cost than nursing care provided by nurses is placing the public health, safety, and welfare at risk. Unsafe care results in higher mortality rates, greater morbidity, unnecessary suffering, and increased utilization of both inpatient and outpatient facilities. The nursing profession has historically demonstrated its responsibility to the public to deliver high quality nursing care by supporting the licensing of nurses, the formulation of standards of nursing practice, and the passage of legislation for mandatory licensure. The threat to the public now caused by the increasing pressure to use unlicensed persons is reason again for boards to take action.

Rationale for Board Involvement

Since the role of the Board of Nursing in each jurisdiction is to protect the health, safety, and welfare of the public by regulating nursing practice, Boards of Nursing have a legitimate concern and have the legal responsibility to monitor any and all nursing activities. This responsibility and its attendant powers are delegated to the Board by the state legislature to fulfill the state's constitutional obligation to protect its citizens. Statutes are enacted by the legislature to grant power to the Board and to provide general mandates pertaining to the regulation of nursing. The statutes also empower and even mandate the Board to adopt applicable administrative regulations.

When the registered nurse delegates selected nursing functions or tasks, the responsibility and accountability to the public for the overall nursing care remains with the registered nurse. Administrative rules often provide what functions or tasks may or may not be delegated and under what conditions delegation may be made. The burden of determining the competency of the person who will perform the tasks and of evaluating the situations rest with the licensed nurse.

Because unlicensed persons perform tasks and functions in one or more of the several categories which constitute the practice of nursing without a license, the Board of Nursing must be involved in their activities. These categories of type of practice by unlicensed persons are:

- Little or no institution or supervision by licensed persons.
- Minimal instruction with return demonstration of particular task with no follow up supervision by licensed persons.
- Limited to moderate instruction with return demonstration of particular task under supervision by licensed persons.
- Moderate to ample instruction with return demonstration of particular task under supervision of licensed persons functioning adequately in assigned areas.

In each instance when the unlicensed persons perform nursing functions without the benefit of instruction or supervision by nurses, this constitutes the practice of nursing without a license and, therefore, should be a concern to the Board of Nursing.

Boards are receiving many requests to allow unlicensed persons to give medications in a variety of settings serving dependent persons. The argument frequently given is that it is a simple technical skill. While this may be true in a few other unique situations, these dependent persons have a high incidence of complex nursing care needs and a high percentage of chronic illness. Hence the nurses' knowledge, judgment and skill are needed to prevent aspiration, to prevent over and under medication, to administer sliding scale insulin, to administer medications by other than the oral

route, and to assess and determine when to administer the multiplicity of p.r.n. medications.

Arguments presented by those who would use unlicensed persons to do complex nursing tasks usually include, for example, "you teach the family to give insulin, to give morphine, to irrigate colostomies". The primary differences with family members are that family members know the patient or client well, family members are only performing the activity for one person; and a nurse has assessed the client, made a nursing diagnosis and planned the care. The nurse teaches the family members what to do for that one client. The nurse evaluates the competency of the family members and instructs them accordingly. When something unexpected occurs, the family members will call the nurse who taught them and this nurse can re-evaluate the entire situation. The change is gauged easily by a family member because of the familiarity with the person gained over a long period of time. This familiarity is not afforded the unlicensed person giving care.

In contrast, the unlicensed person may be doing a task for many clients who are usually not well known to the worker but with a multiplicity of needs.

The unlicensed person has been taught to do a task in a general way but without the knowledge to evaluate each client's needs or problems: The unlicensed persons' lack of knowledge, skill and judgment becomes apparent in their inability to adapt care to individuals' needs based on anything other than rudimentary decision making. Adaptation of care to individual needs requires nursing decisions. Without adequate nursing involvement in the education and supervision of unlicensed persons, patients can be subject to unskilled persons doing nursing tasks without any appreciation of their psycho-social or physical needs. Further, unlicensed persons are reluctant to call for help for fear of being judged incompetent.

Hence, there is a clear difference between care delivered by a family member and that delivered by a paid unlicensed person.

Documenting the Problem

A questionnaire on the activities of unlicensed personnel was circulated to member boards in 1986 with a 71% response rate. The data identified activities by unlicensed and unauthorized personnel to include such things as administration of medications (oral, intramuscular, subcutaneous, intravenous); fresh colostomy irrigations; peritoneal dialysis; and a variety of other nursing activities requiring a nurse's knowledge and judgment. Boards of Nursing responding to the survey reported considerable concern, especially over the wide reporting of administration of medication by a variety of unauthorized personnel in a multiplicity of settings.

The following table summarizes examples of inappropriate utilization of unlicensed personnel:

Population of Recipients	Setting	Source of Problem
1 Individuals of all age groups with non-acute health problems	Physicians' offices	Physician delegation clauses in medical practice acts
2 Dependent persons (persons unable to exercise their rights without assistance)		
a Mentally handicapped	Group homes, community living arrangements, intermediate care facilities, or institutions	State dept. of health or federal guidelines which are misinterpreted or misapplied
b Elderly	Boarding homes, nursing homes, community living arrangements	Dept. of aging or federal guidelines which are misinterpreted or misapplied
c Children (all ages)	K-12 schools, Head Start ctrs., nursery schools	Dept. of education guidelines which are misinterpreted or misapplied
d Chronically ill	Homes, skilled care nursing homes, hospices	Dept. of health and welfare guidelines which are misinterpreted or misapplied
3 Prison populations	Prisons and detention ctrs.	Dept. of criminal justice or corrections dept. regulations which are misinterpreted or misapplied
4 Populations served by non-nurse anesthetists, lay midwives, dialysis technicians, and EMTs	Hospitals, doctors' offices, various settings	Physician delegation clauses in medical practice acts and health dept. guidelines which are misinterpreted or misapplied

Definitions

The following operational definitions are presented as a means to establish common understanding of the terms used in this article:

- **Accountability:** State of being responsible, answerable, or legally liable for action.
- **Delegation:** Nurses entrusting the performance of selected nursing tasks to competent unlicensed persons in selected situations. The nurse retains the accountability for the total nursing care of the individual.
- **Judgment:** A process of forming an opinion or evaluation of a

situation arrived at by reasoning discerning and comparing from premises or general principles.

- **Knowledge:** Understanding, familiarity or awareness acquired through science, art, technique, and experience where known fact, ideas, and skill has been applied.
- **Nurse:** Generic term referring to a person licensed to practice nursing.
- **Nursing practice:** The NCSBN Model Nursing Practice Act defines the practice of nursing as assisting individuals or groups to maintain or attain optimal health status, establishing a diagnosis, planning and implementing a strategy of care to accomplish defined goals, and evaluating responses to care and treatment.
- **Skill:** The ability to use one's knowledge, judgment, and competency effectively and readily in performing a learned psychomotor task.
- **Supervision:** Provision of guidance by a qualified nurse for the accomplishment of a nursing task or activity with initial direction of the task or activity periodic inspection of the actual act of accomplishing the task or activity. Total nursing care of an individual remains the responsibility and accountability of the nurse.
- **Teaching (Instruction):** Includes giving information and ascertaining that the information has been learned through a return demonstration.
- **Unlicensed Personnel:** Unlicensed persons are individuals who are unauthorized to perform nursing acts or tasks that are regulated by the Board of Nursing except pursuant to legal delegation by the nurse. Three categories of unlicensed personnel are identified as follows:
 - Those to whom nurses delegate and supervise;
 - Those whom nurses teach but do not supervise;
 - Those who are not directly or indirectly supervised or taught by nurses.

Conclusions

- Performance of non-nurse delegated and non-nurse supervised nursing activities by unlicensed persons constitutes practicing nursing without a license and is not in the interest of the health, safety, and welfare of the public.
- Language in nursing practice acts that allow for supervision of nursing activities by non-nursing persons is inappropriate.
- The interpretation of physician delegation clauses in medical practice acts that allows for physicians' delegation of nursing acts is inappropriate
- Pieces of care should not be provided in isolation by unli-

censed persons functioning independently of the nurse if the health, safety, and welfare of the public is to be assured.

- Boards of Nursing need to monitor guidelines and regulations of federal and state regulatory agencies with the understanding that the state's Nursing Practice act has the higher legal authority.
- Boards of Nursing need to work to assure evidence of adequate nurse involvement where nursing services are being provided.
- Boards should promulgate clear rules on the utilization of unlicensed persons in all settings where nursing care is delivered.
- Boards need to clearly define delegation in regulation.
- A limited supply of nurses is not an excuse for the inappropriate utilization of unlicensed persons.
- Boards must set standards based on the health, safety, and welfare of the public regardless of cost containment arguments for lowered standards.
- Regulations regarding the delegation of nursing functions must be linked to the disciplinary process.
- Boards need to pursue criminal prosecution when there is clear evidence that unlicensed persons are performing nursing activities.

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- The Model Nursing Practice Act. 1982

Appendix J
Sample IHP Form

Individualized Health Plan

Identifying Information

Student ID _____ IHP initiation date _____
Name _____ Date of birth _____
Address _____ Grade _____ Teacher _____
_____ School _____
Parent/Guardian _____ Telephone [H] _____
[W] _____
Health care provider(s) _____
_____ Telephone(s) _____
Special health needs(s) [Presenting problem(s)] _____

May result in an emergency: No ☐ Yes ☐ > Health planning conference Date _____
May interfere with learning: No ☐ Yes ☐ > Refer to child study team Date _____
Other health impairment: No ☐ Yes ☐ > a) Health planning conference Date _____
b) Refer to child study team Date _____

Health history/present status/health practices:

Interviewer _____ Interviewee _____ Date _____

Sensory assessment:

Assessor _____ Date _____

Physical assessment:

Assessor _____ Date _____

Developmental assessment:

Assessor _____ Date _____

Assessment

Findings:

Nursing diagnosis:

[Individualized Health Plan – continued]

Health Planning Conference _____ Date _____
[for health needs that may result in an emergency and/or require management or monitoring]

Participants

Roles

_____	_____
_____	_____
_____	_____

Goals

Objectives

Timeline

_____	_____	_____
_____	_____	_____
_____	_____	_____
_____	_____	_____
_____	_____	_____
_____	_____	_____
_____	_____	_____
_____	_____	_____
_____	_____	_____
_____	_____	_____

Implemented by

_____	_____
_____	_____

Monitored by

_____	_____
_____	_____

Evaluation/Follow-up Plan _____ Date _____

Parental approval

Case manager

_____	_____
-------	-------

Appendix K
Sample IEP Form

	INDIVIDUAL EDUCATION PROGRAM (IEP) PLAN	DATE	
		IEP Written:	
		Periodic Review Due:	
		Last Comprehensive Assessment:	

A. LEARNER INFORMATION				
Learner's Name <i>Jessie Johansen</i>	Gender <i>F</i>	Grade <i>12</i>	Birthdate <i>12-31-75</i>	ID Number <i>122-34-5678</i>
Street Address <i>406 Any Lane</i>		Primary Language / Communication Mode <i>English, Verbal</i>		
City, State, Zip <i>Swanville, MN 56666</i>				
School of Enrollment <i>Swanville High School</i>		School Phone <i>(612) 123-4567</i>	District Number <i>123</i>	
Learner's Permanent Resident Address <i>same</i>				Resident District Number <i>123</i>

B. PARENT/GUARDIAN INFORMATION			
Name(s) of Parent(s) <i>Mark and Joan Johansen</i>		Phone <i>123-4567</i>	Phone
Parent(s) Address (if different) <i>same</i>		Primary Language <i>English</i>	District Number <i>123</i>
Guardian(s) / Surrogate Parent(s) Name(s) <i>same</i>		☒ Guardian(s) ☐ Surrogate Parent(s)	
Guardian(s) / Surrogate Parent(s) Address (if different) —		Home Telephone	Other Telephone District Number

C. IEP INFORMATION		
Primary Disability <i>Learning Disability</i>	Federal Childcount Setting <i>Regular Education</i>	IEP Type ☐ Initial ☒ Annual ☐ Interim
IEP Manager Name <i>Sue Hanson</i>	Position <i>Special Education Teacher</i>	Telephone Number <i>345-6789</i>

D. IEP PLANNING MEETING		
Title	Names of All Team Members	Signature (if present)
Parent	<i>Mark Johansen</i>	
Parent	<i>Joan Johansen</i>	
Learner	<i>Jessie Johansen</i>	
Administrator or Designee	<i>Sarah Hoffman</i>	
Special Education Teacher	<i>Sue Hanson</i>	
Regular Education Teacher (K-12 only)	<i>Tim Johnson</i>	
<i>sister</i>	<i>Cindy Johansen</i>	
<i>SSB counselor</i>	<i>Harold Batens</i>	
<i>School guidance counselor</i>	<i>Mildred Fortney</i>	
<i>Support Services, .MTC</i>	<i>Sharon McElroy</i>	

COPIES:

☐ Learner File☐ Parent☐ IEP Manager

Learner's Name: Jessie Johansen

E. PRESENT LEVELS OF PERFORMANCE & LEARNER-BASED NEEDS	
Carefully consider and document data from all sources in the following areas: (Include information and observations provided by parent[s] and learner.) • Intellectual / Cognitive Functioning • Academic Performance • Communicative Status • Motor Ability • Sensory Status • Health / Physical Status • Emotional and Social Development • Behavior and Functional Skills *† • Secondary Transition (must be summarized for all learners who have reached 9th grade or age 14) A. Jobs and Job Training B. Recreation and Leisure C. Home Living D. Community Participation E. Post-Secondary Training and Learning Opportunities * Identify post-school outcomes for each transition area. † If the team determines that there are no transition needs in one or more areas, write a statement to that effect and the basis for this determination.	
PRESENT LEVELS OF PERFORMANCE	LEARNER-BASED NEEDS
<i>Post-secondary Education</i> <i>Future adult goal: I want to work in the law enforcement field, maybe as a dispatcher. I plan to go to a post-secondary school that has training in law enforcement.</i> <i>Present level of performance: I have been a police explorer for two years. I have visited several technical colleges and community colleges and have checked into housing and public transportation at each site. I keep track of all this information in my transition folder. I understand my personal strengths and weaknesses and have learned how to advocate for the accommodations I need to be successful.</i>	<i>I need to apply at the postsecondary schools I like the best, figure out how to pay for it, and work at getting the accommodations I think I will need to successfully complete the program.</i>

Learner's Name: Jessie Johansen

F. ANNUAL INSTRUCTIONAL GOALS & SHORT-TERM OBJECTIVES		
GOAL <i>In writing the goal statement, indicate the direction of change, the behavior to be changed, and the expected ending level of performance.</i>		GOAL # ____ OF ____ GOALS
<i>I will increase preparation activities for fall, 1994, entry into a post-secondary school that offers a program in my interest area from having visited several schools to completing an application and being accepted, finding financial aid, and setting up accommodations by graduation this spring..</i>		
SHORT-TERM OBJECTIVES <i>There must be more than one objective for each goal. For each objective include attainment criteria and evaluation procedures.</i>	Review Date	Degree of Progress
1. <i>Given registration materials for post-secondary school of interest, I will complete the necessary forms with 100% accuracy by the end of the first semester as determined by my school counselor.</i> 2. <i>Based on my learning strengths and weaknesses, I will correctly list all the resources available at the schools I am interested in before enrolling, as determined by my special education teacher.</i> 3. <i>I will travel by city bus to my SSB counselor's office and meet with my counselor at least four times over the course of the school year for assistance in planning and funding my post-secondary education as monitored by my SSB counselor.</i>		

G. PERIODIC REVIEW SUMMARY OF GOAL & OBJECTIVES
The following is the status of the learner's goal and objectives: ☐ Goal achieved. ☐ Meets learner's current needs and will be continued without changes. ☐ The non-significant changes listed below will be made without an IEP meeting unless you contact us. ☐ Does not meet learner's current needs and the significant changes listed below require a revised IEP. We will be in contact soon to schedule a meeting.
NOTE TO PARENT(S): You are entitled to request a meeting to discuss the results of this review.

Learner's Name: Jessie Johansen**H SPECIAL EDUCATION & RELATED SERVICES****SPECIAL EDUCATION SERVICES**

SERVICE PERSONNEL CODE <i>(see reverse for codes)</i>	NAME OF SERVICE PROVIDER & PHONE NUMBER	SERVICE CATEGORY CODE <i>(see reverse for codes)</i>	BUILDING NAME & ROOM NUMBER	FRE- QUENCY	MINUTES PER WEEK		TYPE OF SETTING						DATE SERVICE BEGINS	DURA- TION OF SER- VICES	
					INDIRECT	DIRECT	check one			check one					
							CLASS	GROUP	INDIVIDUAL	GENERAL	SPECIAL	INTEGRATED			OTHER
01	Sue Hanson 345-6789	49	Swanville High, Rm 207	daily	75	150	x				x			9-93	6-94

RELATED SERVICES AND JUSTIFICATION

35	Mildred Fortney 456-7890	35	Swanville High, Rm 101	monthly		10			x	x				9-93	6-94
----	-----------------------------	----	---------------------------	---------	--	----	--	--	---	---	--	--	--	------	------

Justification: *Information about postsecondary schools, application process, and accommodations*

--	--	--	--	--	--	--	--	--	--	--	--	--	--	--	--

Justification:

TRANSITION SERVICES (for age 14 and above)

AGENCY NAME	NAME OF SERVICE PROVIDER & PHONE NUMBER	BUILDING NAME	FREQUENCY	AMOUNT OF SERVICE TIME	DATE SERVICE BEGINS	DURATION OF SERVICES
State Services for the Blind	Harold Batens 426-1234	Park Plaza	at least quarterly	minimum 8 hours	10-93	ongoing

Interagency / Organization Linkages (Identify activities, funding responsibilities, etc.):
assistance in planning and funding postsecondary education

Support Services Morton Tech. College	Sharon McElroy 426-9876	Morton Tech College	as needed	about 4 hours	10-93	throughout college career
---	----------------------------	------------------------	-----------	---------------	-------	------------------------------

Interagency / Organization Linkages (Identify activities, funding responsibilities, etc.):
provide information on technical college options and accommodations

Learner's Name: Jessie Johansen**I. ADAPTATION OF GENERAL & SPECIAL EDUCATION**

Describe changes in general and special education that will be made to permit successful accommodation and education of the learner (e.g., grading, credits, staff, transportation, facilities, materials, equipment, technology, adaptive devices, curriculum, methods, coordination of support services, vocational services and equipment, and other services):

Are Regulated Behavioral Interventions required for this learner?

(If yes, attach behavior plan as described in M.R. 3525.2925.)

☐ Yes ☐ No

Are general education secondary graduation standards being modified?

(If yes, attach team determination documentation as described in M.R. 3525.3150.)

☐ Yes ☐ No

Are extended school year services required for this learner?

(If yes, attach extended school year justification as described in M.R. 3525.2900 Subp. 1.H.)

☐ Yes ☐ No

J. LEAST RESTRICTIVE ENVIRONMENT (LRE)

Explain why the proposed placement is the most appropriate and the least restrictive. (Describe any other options considered.)

K. DESCRIPTION OF ACTIVITIES WITH LEARNERS WITHOUT DISABILITIES

For a learner who is served more than half-time in a special education setting, include any activities in which the learner will be participating with learners who do not have disabilities (e.g., lunch, assembly periods, club activities, field trips, community instruction or experiences, and other special events):

Activity	Frequency	Amount of Time

LENGTH
OF DAY

☐ Check here if the learner's school day is shorter than that of peers without disabilities.
(If checked, Commissioner of Education approval is required.)

NOTE:

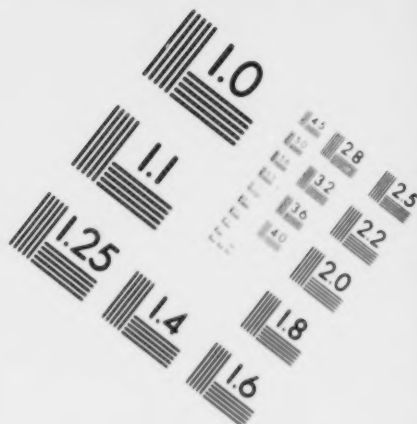
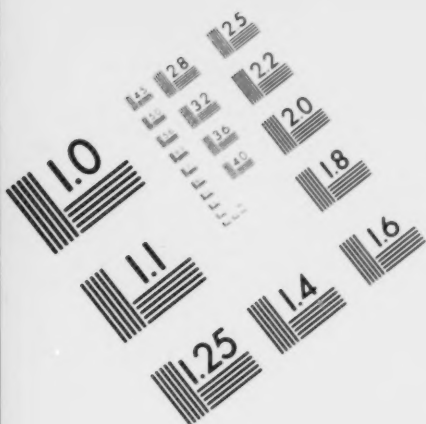
Attach "Notice of Special Education Services."



AIM

Association for Information and Image Management

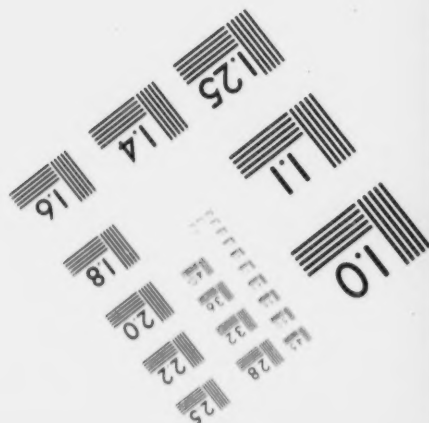
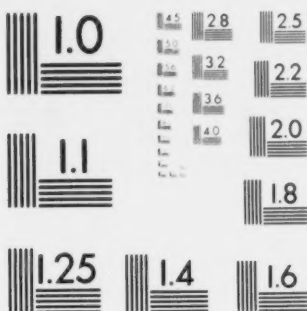
1100 Wayne Avenue, Suite 1100
Silver Spring, Maryland 20910
301/587-8202



Centimeter



Inches



MANUFACTURED TO AIM STANDARDS
BY APPLIED IMAGE, INC.

Service Personnel Codes

- 01 Teacher
- 02 Supervisor / Coordinator
- 03 Lead Teacher
- 04 Physical Therapist
- 05 Occupational Therapist
- 06 School Nurse (*Report only time in levels V and VI.*)
- 07 Program / Instructor Assistant Levels I, II, III
- 08 Program / Instructor Assistant Levels IV, V, VI
- 09 Director of Special Education
- 10 Assistant Director
- 11 School Social Worker
- 12 School Social Worker Aide for Indian, Hispanic, or Southeast Asian Students
- 13 School Psychologist
- 14 Audiologist
- 15 Adaptive Physical Education Specialist
- 16 Consultant
- 17 Other
- 18 Child Find Facilitator
- 19 Public Information Facilitator
- 20 Child Study Due Process Facilitator
- 21 Alternative Program Facilitator
- 22 Secretary
- 23 Substitute Teacher
- 24 Certified Occupational Therapy Assistant (COTA)
- 25 Other Certified Therapist
- 26 SEIMC Management Personnel
- 27 Vision Media Assistant (brailist / L.P. typist)
- 28 Interpreter for the Deaf
- 29 Orientation and Mobility (O & M)
- 30 Due Process Hearing Officer
- 31 Clinical Psychologist
- 32 Behavior Analyst (prior approval)
- 33 Regional Special Programs Supervisor
- 34 Assistive Technology Specialist
- 35 School Counselor

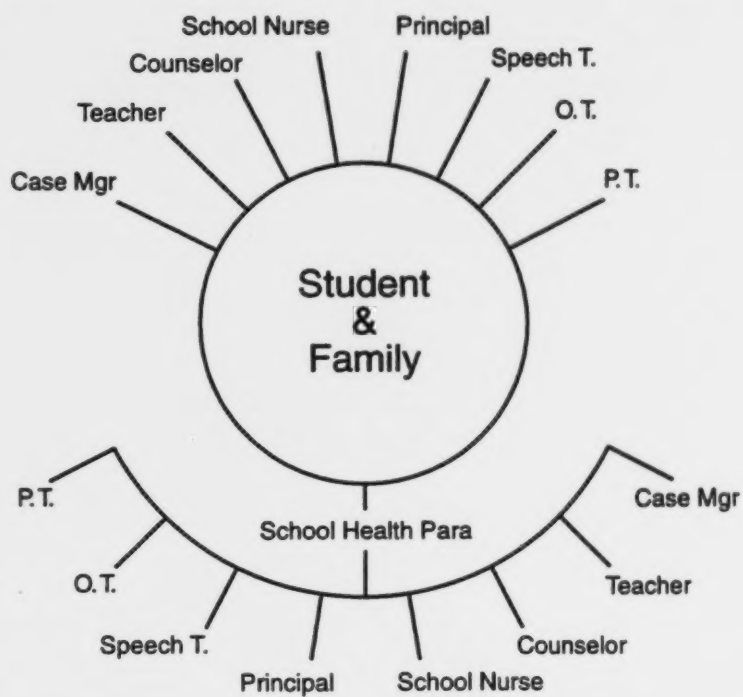
Service Category Codes

- 425 Early Childhood Handicapped
- 440 Mildly Mentally Impaired
- 450 Moderately Severe Mentally Impaired
- 460 Physically Handicapped
- 465 Hearing Impaired
- 470 Speech / Language Impaired
- 475 Visually Handicapped
- 490 Specific Learning Disability
- 491 Other Health Impaired
- 492 Autistic
- 493 Emotional / Behavioral Disorder
- 494 Traumatic Brain Injury

Appendix L

"Chain of Command"

Diagram



Appendix M

Body Mechanics

Explain the
Procedure



Squat



Get Help



Lift with
Thigh
Muscles



Have a
Wide
Base of
Support



Be Smooth
and
Synchronized



Move in
Close



Turn with
Your Feet



Use an
"Internal
Girdle"



Push or Pull



Use
Lifting
Aids



Appendix N

Diapering Procedure

Preparation

- 1 Wash hands with soap and running water.
- 2 Assemble supplies within reach:
 - Clean disposable diaper
 - Disposable wipes or paper towels
 - Roll paper or nonabsorbent paper sheets
 - Disposable gloves (when used)
 - Optional: ointment, cotton swabs, clean clothing
- 3 Cover diapering table and waste bin lid with nonabsorbent paper. The table needs to be the length of the child; leave about a twelve inch overhang at the feet or have clean paper sheets within reach.
- 4 Put gloves on.

Contamination

- 1 Put the child on the table. Keep one hand on the child the entire time he or she is on the table. Keep others away from the diapering area. Remove the child's clothing; put soiled clothing aside.
- 2 Remove the soiled diaper. Loosen diaper tabs; roll diaper inward. Using the foot pedal to open, place the diaper directly into the waste bin or place it on the paper-covered lid. (It must be out of the child's kick space or reach.)
- 3 Cleanse the diaper area of the child. Clense from front to back and include skin creases. Use the child's own disposable wipes or the three paper towel method (soapy-rinse-dry). Place the wipes in the waste bin or on its lid. Dry child's skin well.
- 4 Remove gloves and place them in/on waste bin.

Cleaning Phase

- 1 Put clean paper under the child; fold the overhang at the feet or use a clean sheet.
- 2 Use ointment as ordered; apply with clean swabs or gloves.
- 3 Diaper and dress the child.
- 4 At the sink, use soap and running water to wash both your hands and the child's.
- 5 Return child to the play area.

Clean-up

- 1 Dispose of soiled items: Place diaper in a small bag (optional). Put diaper, wipes, paper towels, changing paper, cotton swabs,

and gloves into the plastic-lined, foot-operated waste bin. Put any soiled clothing in a plastic bag for parent to take home.

- 2 Clean and disinfect the diapering table, waste bin lid, and faucet handles.
- 3 Wash hands with soap and water for twenty seconds using the posted procedure.

Communicate

- 1 Record the diaper change.
- 2 Report any concerns to parents (unusual color, odor, frequency, or consistency of stool; rash).

Appendix O
Hand Washing Flyers

HANDWASHING

PROCEDURE

The single most effective thing you can do to prevent the spread of disease is to correctly wash your hands and the children's hands thoroughly and often.

BOTH STAFF & CHILDREN WASH:

HOW

- 1 Remove jewelry; push up sleeves. **Wet** hands with warm, running water ($110^{\circ} \pm 10^{\circ}$ F).
- 2 **Apply** liquid soap.
- 3 **Wash** hands for 20 seconds; include palms, backs, between fingers, thumbs, fingernails, and wrists. Use a nail brush after contact with stool or if a food handler.
- 4 **Rinse** well with fingertips pointed down.
- 5 **Dry** hands with a hot air dryer or a paper towel.
- 6 **Turn off faucet** with a paper towel. This avoids contamination. Throw paper towel into a plastic-lined waste container.

WHEN

- When you **arrive**.
- Before or after you eat; before you prepare or serve **food** or set the table.
- Before you prepare or give **medication**.
- After using the toilet; before and after **diaper** changes.
- After you handle items or children soiled with **body fluids or wastes** (blood, vomit, stool, urine, drool, eye matter).
- After you cough, sneeze, or blow your **nose**.
- After playing with or caring for **pets**.
- After playing **outside**.
- Before and after using water tables or **moist items** like clay.
- Whenever hands **look, feel, or smell unclean**.

Adapted from materials prepared by Hennepin County Community Health Department with the support of epidemiologists and child health care consultants from the Twin Cities area state and local health departments.

HANDWASHING

STEPS



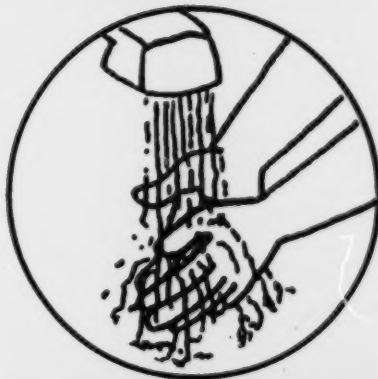
1 • WET



2 • SOAP



3 • WASH



4 • RINSE



5 • DRY



6 • TURN OFF WATER

Appendix P

Questions to Ask Regarding Doctors' Services

You may want to share this handout as a reference for parents who are living with an individual who is medically fragile or has a physical disability.

Questions to Ask Before a Doctor Sees Your Child

When Interviewing Doctors by Telephone

- 1 Do you see children with disabilities in your practice?
- 2 Do you have experience with children who have (your child's disability)?
- 3 Would you be comfortable working in a medical team situation with other doctors who will be seeing my child?
- 4 Can you schedule extra long appointments?
- 5 Who sees your patients when you are not available?
- 6 Which hospital do you use for patients who require hospitalization or hospital tests?
- 7 What are the facilities of this hospital for children and families like mine?
- 8 If my child were hospitalized, would I be allowed to stay with him or her?
- 9 After you've examined my child, can you arrange for one of your staff to watch him or her for a few minutes so we can talk alone?
- 10 Would there be any additional charges for any of these arrangements?

When Scheduling an Appointment

- 1 I will be needing a longer appointment than most families. Can we schedule a time when we can have a double appointment?
- 2 My child has difficulty waiting patiently: is the first appointment of the morning available or one right after lunch break?
- 3 If you don't make appointments, what times of day or which days of the week are least busy?

Questions to Ask When a Doctor Has Seen Your Child

Questions about an Illness

- 1 Can you make a diagnosis at this time?
- 2 Would you recommend a second opinion or a specialist for this illness?
- 3 Should anything be done immediately? What should we be doing over the next few days? Are there any long-term needs/concerns?
- 4 When will the child begin to feel better? How long does this illness usually last?
- 5 Are there any symptoms I should be aware of to monitor this illness? What are the indications that he or she is getting better? What are the indications of any complication or worsening?
- 6 If I do notice any signs of complications, how can I contact you after office hours? In an emergency, whom should I call?
- 7 When can he or she go back to school? Are there any special precautions of which the school should be aware?

Questions about General Check-ups and Development

- 1 Is he or she within the range of normal height and weight for his or her age? Is he or she growing at a normal rate?
- 2 Is he or she developing normally in the areas of physical abilities, speech, vision and cognitive development?
- 3 What are the age ranges typically during which children develop these abilities? Am I right to be concerned at this time? When should I become concerned?
- 4 Do you think some developmental screenings should be done at this time? Do you administer any of these tests yourself as part of the regular check-up? (If the answer is no, you may want to have the doctor write a report indicating a concern over development in a particular area which you can send to the school staff working with your child to request that they test your child or arrange for appropriate testing. If your child is not school age, you may request these results be sent to the school system to request early intervention screening.
- 5 What are the next developmental stages we should be watching for? What can we do to help our child?
- 6 Should we be consulting with the early intervention program and/or therapists for our child? Will you collaborate with the school by sending copies of your evaluations or writing a report specifying my child's delays which I can use in talking to the local school system?
- 7 Can I give the school or early intervention team your phone number so they can call if they have any questions?

- 8 Do you think we should be consulting with any other specialists at this time? If yes, what are your recommendations? Can you refer us?

Questions about Medications

- 1 When should I give this medication?
- 2 When the prescription says "three times a day" does that mean every eight hours including during the night, or three times during the daytime?
- 3 When my child goes back to school, will he need to take this medicine during school hours or can it wait until he gets home?
- 4 Should the child take this medication before, during or after meals?
- 5 Are there any foods which should not be mixed with this medication?
- 6 How long should he take this? Should he finish the bottle or stop when the symptoms go away?
- 7 If your child has other medications he is currently taking talk about those work and how they do not work together.
- 8 Can he take this medicine at the same time? Are there any possible side effects or allergic reactions I should be aware of? How will I recognize them? What should I do if I think he or she is having a reaction?
- 9 Does this medicine need to be stored at a special temperature, that is, does it go bad if the medicine gets too hot or too cold?

Questions about Tests

- 1 What do you expect to learn from these tests?
- 2 Have these tests been given to my child before? Can we coordinate any of the earlier results with these?
- 3 Does the school or public health clinic also do these tests? Is there any reason not to have them done there to save on expenses?
- 4 How long will these tests take and what is involved in them?
- 5 Is there anything I should tell my child about these tests which will help prepare him?
- 6 Can he or she eat before coming?
- 7 Are there any precautions I should take either before or after these tests?

Questions about Referrals to Specialists

- 1 Specifically, why is this referral being made?
- 2 Is this a second opinion or are we seeing the specialist for a diagnosis?

- 3 Are there records I should take with me or will they be sent in advance?
- 4 Is this specialist comfortable with children like mine? Has he or she been fully informed about my child's disability or would it be useful for me to give him a call?
- 5 Who will get the reports of this evaluation? Who will be interpreting them? Who will be discussing these reports with me?
- 6 What are this specialist's rates? Can arrangements be made to help cover these expenses?

Questions about Surgery

- 1 What exactly will this surgery do or allow my child to do?
- 2 What are the consequences of not doing it?
- 3 Would there be any advantage in waiting to see if the situation improves?
- 4 How long will my child be in the hospital?
- 5 How long will it take my child to fully recover from this surgery?
- 6 Will we need any special equipment or help at home after release from the hospital?
- 7 What are the possible complications or side effects?
- 8 Should we get a second opinion? Do you think any additional surgery will be necessary?

Questions about Hospitalization

- 1 Can you estimate the length of my child's stay in the hospital?
- 2 Who will be the attending doctors?
- 3 Can I stay with him or her overnight?
- 4 Is there any information I can give him or her now to prepare for this?
- 5 When is check-in time?
- 6 Does the hospital have a program for children explaining about hospitals which would be helpful for my child?
- 7 Will this be covered by my insurance?

Hickson, G.B., Stewart, D.W., Altemeier, W.A., & Perrin, J.M. (1988). "First Step in Obtaining Child Health Care: Selecting a Physician." *Pediatrics*, 81, 333-338. Taken from the National Information Center for Children and Youth with Disabilities (NICHCY). This information is in the public domain.

Appendix Q

Modifying the Environment for Individuals with Physical Disabilities

This list can be used as a starting point to think of numerous accommodations that can be easily arranged to help individuals achieve better in a given situation. Feel free to add your ideas to this list and to share solutions from your own experience about ways to develop accommodations.

- Suggest seating where the individual will be most comfortable and have the greatest access to materials, equipment, lavatory facilities, and emergency exits.
- Inform teacher/supervisor, etc. of any medical considerations for the individual. These include such information as prescribed medication, possible side effects of medication, stamina limitations, physical limitations, and emergency procedures. Then the teacher/supervisor should remember to monitor the effects of medication. Feedback should be provided about classroom and laboratory behavior after medication has been taken by the learner.
- Some individuals may have to be released from class/work periodically to use lavatory facilities, administer insulin injections, take medication, or go to the clinic for a short rest. Be sure the teacher/supervisor knows this.
- It is helpful for teachers/supervisors to release individuals who have wheelchairs, crutches, canes, or braces from class several minutes early so that they may get where they need to go on time. A peer volunteer can help them travel from one place to another. This also fosters positive interpersonal relationships.
- Peer volunteers can be selected to help take notes or review information after direction/instruction has been given.
- If adaptations must be made, ask the individual with the fragile condition or physical disability to help determine exactly what changes must be made. They can often suggest modifications that are inexpensive and easy to create.
- Place materials and supplies to be used by the individual on lower shelves in storage areas.
- Use the demonstration technique whenever possible to provide concrete instructional examples.
- Allow these individuals longer periods of time to complete tasks, if necessary.

- Allow the individuals to tape assignments and tests if they are unable to write.
- Many individuals with physical disabilities have orthopedic appliances such as wheelchairs, canes, crutches, and braces. These appliances should be considered in adapting the program and facilities and/or instruction.
- Overhead projectors produce larger images than writing on a chalkboard.
- Special materials such as large-print books, oversized pencils, pencil grips, clipboards, and easy-to-grasp tools with larger handles should be provided as necessary.
- Adaptive aids such as lapboards for wheelchairs, wrist harnesses to hold pens, and bookholders attached to wheelchairs help individuals adapt to the program.
- Individuals who are in wheelchairs frequently need to redistribute their weight because of poor circulation.
- Provide tutoring by a peer tutor, teacher's aide, parent volunteer, or home-bound instructor if the individual is behind because of frequent absences.
- The other individuals in a given group who do not have a disability should be openly and accurately informed of their disabled peer's particular physical condition and advised how they can assist, if necessary. Honesty is best rather than trying to ignore or hide the condition.
- Many conditions require the use of an orthopedic aid (e.g., wheelchair, brace, cane). Help the teacher/supervisor know how these aids are used and even assist in their maintenance.

Appendix R

Death Education for Teachers: a Refocused Concern Relative to Medically Fragile Children

By Claire Thornton and Junean Krajewski

In today's society, teachers are primary role models for elementary-age students. For these children, most of the day is spent under the care and guidance of an adult whom they regard as a person that they can trust and turn to in time of need. Teachers not only relay a body of academic knowledge to children, but also teach them life skills that will enable them to function as adults in an ever-changing technological society. While academic knowledge is important, it is only one facet of our complex human condition. Children also need to learn healthy emotional responses to life's challenging situations.

One such situation occurs when a terminally ill child becomes a student in a classroom. The issues and challenges surrounding his or her presence and, when applicable, following his or her death, can provide an opportunity for growth on the part of both the teacher and classmates. The term "medically fragile" has been used to refer to children who have life threatening or terminal health-related conditions. Children included in this category may have cancer, cystic fibrosis, muscular dystrophy, or AIDS, as well as other conditions, and frequently may require such specialized care as catheterization, tube feedings, and frequent medication (Kirk & Gallagher, 1989).

The current number of children who could be considered medically fragile is difficult to determine. If the children's needs warrant special services under PL 101-476, those statistics are available. However, many children with terminal illnesses may not opt for or be eligible to receive special services. Others may be included in other categories such as multiple disabilities. Therefore, a brief look at some available statistics on subgroups of this population reveals only a partial accounting of the number of medically fragile children. According to the Centers for Disease Control, the number of children with AIDS in 1988 was 1,065. The projected number for 1991 was 3,000. In addition, The Twelfth Annual Report to Congress on the Implementation of the Education of All Handicapped Act stated that 46,639 children have other health impairments that require special education services (Smith & Luckasson, 1992). With the increased mainstreaming of special

needs youngsters into regular classes and schools, the chances that a teacher will have a terminally ill child in his or her classroom have increased. Such a possibility presents a complex myriad of issues for the field of education in general and for the classroom teacher in particular.

While some literature (e.g., Brennan, 1983; Molnar-Stickels, 1985; Oaks & Bibeau, 1987) maintains that the school is the logical place to educate children about death, there appears to be some debate as to who should be responsible. Numerous articles (e.g., Bascue & Kruger, 1974; Bertoio & Allen, 1988; Getson & Benshoff, 1977; Heath, 1985) discuss the topic as belonging in the counselor's domain while other literature considers the health educator as the focal person for such instruction (Eddy, St. Pierre, Wesley, & Davis, 1985; Molnar-Stickels, 1985). However, it is the teacher who typically has a developed rapport with the children and daily interacts with them throughout the academic school year as a significant adult and role model. It is also the teacher who has expertise in child development and who serves as a vital connecting link between the home, school, and the greater community. Therefore, the teacher, as a trusted and responsible adult, a source of knowledge, and as a person who can network with others in the community, has the resources and the opportunity to comfortably respond to the questions and concerns that children might have on this topic.

Considering the current and increasing focus on the inclusion of medically fragile children in the mainstream, surprisingly little literature addresses the teacher and his or her role as the primary adult encountering the dying child, grieving child, and the parents of both groups. Thus, this article will address the roles and responsibilities of teachers in regard to (a) self-awareness and education, (b) children's understanding and reaction to death, and (c) responding appropriately to parental issues and concerns.

Roles and Responsibilities: An Overview

Whereas many teachers acknowledge that children dealing with a death may need special support, many others may not be aware that such a need exists. Other teachers may question their responsibility or the appropriateness of the subject matter in the school curriculum. Teachers who are unable to help children who are grieving may complicate the process and miss an important opportunity to help children cope with stress (Molnar, 1983; Oaks & Bibeau, 1987). Since teachers maintain constant, almost day-to-day contact with children, they are very significant adults in most children's lives. They can serve as both a support for the children (Oaks & Bibeau, 1987) and an important role model (Cohn, 1987; Cunningham & Hare, 1989).

The importance of helping children perceive and respond to death in a healthy manner is critical to their continuing develop-

ment in emotional, psychological, and intellectual areas (Molnar-Stickels, 1985). While some teachers may choose not to respond (perhaps because they do not know what to say or how to act), such a lack of response may increase children's fears and anxieties (Molnar Stickels, 1985). Obviously the need exists to educate teachers and administrators regarding the roles of the school and school personnel, the importance of the topic in the curriculum, and the resources available. It is important to note that as teachers become more aware of the implications the topic of death may have for them and their classrooms, they may begin to experience some discomfort.

Teachers' Roles and Responsibilities: Self-Awareness

The existence of personal discomfort on the part of a teacher dealing with the topic of death is well substantiated (Cunningham & Hare, 1989; Molnar-Stickels, 1985; Oaks & Bibeau, 1987). Obviously, the teacher's values, feelings, and experiences related to death are potential influences on his or her reaction to children dealing with death. The resolution of these feelings and reactions is important to interacting with a bereaved child. Some experiences that can help a teacher explore his or her own thoughts, feelings, and attitudes may be part of a formal inservice training session that examines death and/or related issues. However, such exploration may be done individually. Suggestions include reading appropriate literature (books or journals), writing a personal obituary, discussing death and dying with other professionals, talking to a mortician, and visiting a nursing home (Bascue & Kruger, 1974; Getson & Benshoff, 1977; Nelson, 1977). As a teacher examines death, religion and its impact on this issue will often become apparent. This may present some concern for the teacher who perceives the connection as breaching the separation between school and religion. To reconcile this concern, the teacher might find it helpful to discuss death with someone of his or her own personal religious background as well as with someone with no religious affiliation or commitment. Such experience might better prepare the teacher to perceive the child's point of view in the religious realm (Getson & Benshoff, 1977).

It seems appropriate to note that with the increase of culturally different children within our schools, some teachers will need to research specific cultural beliefs relative to death. Some research indicates that even a very short teacher in service on death education may result in less fear of death and a more comfortable feeling in discussing death on the part of participants (Molnar Stickels, 1985). As the teacher becomes more comfortable dealing with death, several issues arise. Questions about how to react to children's inquiries and behaviors as well as how to synthesize all the information into meaningful responses to grieving children will arise.

Teachers' Roles and Responsibilities: Education

Many teachers understand the need for their active involvement, have explored their personal feelings, attitudes, and want to respond appropriately with grieving children and parents. The literature suggests that prior to responding, the teacher should have an understanding of the behaviors bereaved children may exhibit, the duration of children's grief, and the stages children may go through in grieving (Eddy, et al., 1985). Additionally, the teacher should be familiar with both the relationship of concepts about death to the developmental stages and the variables that impact the child's progress through the stages. This vital information is summarized below.

Common Student Behavior in Reaction to Death

- Does not complete assignments.
- Frequently asks for the directions to be repeated.
- Complains of headache, stomach aches, loss of appetite.
- Lacks energy.
- May be irritable, nervous, cry, and have mood swings.
- May exhibit inattention, daydreaming.

Children: Understanding and Reacting to Death

When children experience the death of a classmate, they struggle intellectually with understanding what has transpired and emotionally with accepting the loss. First of all, it is important to realize that children's understanding of death is directly related to their cognitive development. Children between the ages of three and six are in Piaget's Preoperational Stage of development. At this stage, the child is egocentric and may believe that he or she is personally responsible for an individual's death by having thought, "I wish she'd go away" or "I wish he'd drop dead." The children may struggle with guilt if the thoughts and feelings become a reality. At this level, the child does not understand that death is forever because the child does not have a developed sense of time. Children think that the dead person is still living in the coffin and becomes active at night. To summarize, children at this level of cognitive development do not perceive death as a natural, irreversible, and universal part of life.

In comparison, children who are between the ages of seven and ten are in Piaget's Concrete Operational Stage. Children at this level are concrete in their thinking and personify death as a shadowy, sneaky figure – a skeleton or a ghost who appears late at night. Because they personify death, they believe that they can run away from "it", outsmart "it", or hide from "it." They are also inquisitive as to what death means and are open to receiving honest and direct answers. They may ask questions that seem gruesome

such as, "Do worms eat through the coffin?" (Garanzini, 1987). The following example illustrates why teachers should respond to children's questions without using any figurative language.

One teacher told her primary grade class that a student had died "because God picks the most beautiful flowers in the garden and takes them to heaven." One child, at the concrete level of cognitive development, became a behavior problem in order to guarantee he wouldn't be picked (Breig, 1987). At this age, however, children perceive death as final and around the latter ages of this level, inevitable.

Around the age of twelve, children enter Piaget's stage of Formal Operations and have the cognitive ability to think abstractly about the concept of afterlife and fully comprehend what death means (Garanzini, 1987; Molnar, 1983). It is important for the teacher to consider the children's cognitive development prior to responding to their questions and concerns. While literature examines a child's reaction to death, classmates will also have concerns and problems dealing with the possible and impending death of a medically fragile peer. In this instance, the level of cognitive development should also be considered. One fifth-grade teacher reported a range of emotions among his students when a peer was diagnosed with leukemia. Reasoning at the concrete operational level, many students believed that death could be avoided, and therefore the illness and subsequent death were the result of irresponsible and negligent care. These students expressed concern that leukemia could be contagious and were fearful of attending school or interacting with their classmate. A visit to the classroom by one of the attending physicians who explained leukemia and the child's treatment helped answer these students' questions and allay their fears.

Children at either the preoperational or formal operations stages of development would express other concerns that would necessitate different responses. Also, depending on the developmental stage of the children, the topic of death could be discussed in the classroom through the use of literature. Ordal (1984) presents a comprehensive list of appropriate books or stories that deal with death in a positive way. Other interventions, as well as a list of agencies and organizations and films/videos, are included in Heath (1985). See the section below for various ways to help children.

Guidelines for Helping a Child

- Encourage children to express their feelings but don't push for too much or require that they do so.
- Be honest. Answer questions truthfully and express your own emotions honestly.
- Keep it simple. Discuss death in terms children can understand. Don't give them more information than they can handle at their developmental level.

- Relate to children at their developmental level. If you're unsure of their level, ask them for their interpretation of what happened.
- Be patient. Be aware that children may repeat the same questions as they seek reassurance and deal with confusion and fear. Also remember that the length of grieving differs from child to child and may last for some time.
- Don't pre-establish expectations. Each child deals with death differently.
- Do suggest some ways a child can memorialize the person such as planting in that person's honor, drawing a special picture, or writing something about the person.
- Accept the child's feelings, perceptions, and reactions. Allow for differences of opinion, doubt, and questions.
- Refer the child, and perhaps the parents to other support people or services if necessary.
- Prepare children for the continuation of their life. Reassure them that they will feel better after a time and that the time differs from person to person. Children should be assured that, in time, they will be able to play and have fun and that doesn't mean they love the person any less (Breig, 1987; Cohn, 1987; Cunningham & Hare, 1989; Eddy et al., 1985; Faivre, 1981; Garanzini, 1987; Heath, 1985).

Providing Parental Assistance

Teachers should also be prepared to respond to parent concerns. Teachers may be asked to respond to the parents of the dying child or the deceased child as well as to the parents of grieving classmates. Each situation will require a slightly different perspective. Open communication will enable the teacher to share supportive materials and information with concerned classmates that is in keeping with the dying or deceased child's family's request for privacy. The topic of death has long been regarded as "taboo" in our society. Certainly its inclusion within the school curriculum might generate some controversy and discussion. However, it is apparent that death is a reality that both children and adults must perceive in the most accurate way possible. While the topic can be addressed before or after a death, the literature overwhelmingly addresses the need for well-prepared teachers who can assist and support children as they encounter this stressful occurrence. Teachers need self-awareness regarding their own attitudes and concerns regarding this topic. They need an understanding of children's perception of death and how to respond appropriately. Finally, they need to be able to address parental issues and concerns. Classroom teachers are the connecting link between the school, home, and the greater community. Because of this, they

fill multifaceted roles. They are interactive facilitators, informal classroom counselors, child development specialists, and resourceful networkers. They are significant adults to the children they serve. With appropriate preparation, teachers can have a positive impact in teaching children healthy emotional responses to one of life's most challenging situations. With the inclusion of an increased number of medically fragile children in the mainstream of our schools, the time for an active response is now.

Ways to Assist Parents

- Contact the parent by phone and/or by note to express concern or sympathy and to open channels of communication.
- Schedule a parent conference if desired by the parent.
- Distribute helpful articles focusing on parent concerns.
- Recommend children's books (to be shared at home) that deal with the topic in a sensible manner.
- Distribute written guidelines and/or suggestions especially if an individual situation requires more specific attention.
- Make available a list of mental health clinics and/or professionals available for assistance.

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Appendix S

Estimated Prevalence of the Major Uncommon Diseases & Conditions in Children

The conditions listed below are considered "uncommon" because they each have a frequency of less than one percent in the child population. This information was adapted from Gortmaker, S.L., & Sappenfield, W. Chronic Childhood Disorders: Prevalence and Impact. *Pediatric Clinics of North America* (1984) 31: 3-18.

<i>Disease/Condition</i>	<i>Prevalence per 1,000 Children</i>
Congenital heart disease	7.0
Seizure disorders	3.5
Cerebral palsy	2.5
Arthritis	2.2
Paralysis from injury	2.1
Diabetes mellitus	1.8
Cleft lip/palate	1.5
Down syndroms	1.1
Blindness	0.6
Mental retardation due to fragile x chromosome	0.5
Sickle cell disease	0.5
Neural tube defect	0.5
Autism	0.4
Cystic fibrosis	0.3
Neurofibromatosis	0.3
Hemophilia	0.2
Duchenne muscular dystrophy	0.1
Acute leukemia	0.1
Deafness	0.1
Other hereditary metabolic disorders	0.1

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Eating Disorders Program, Riverside Medical Center, Riverside & 25th Avenue S, Minneapolis, MN 55454. Telephone 612/371-6600.

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Module Six

Working with Individuals Who Are Medically Fragile or Have Physical Disabilities

Prepared by
Institute on Community Integration (UAP)

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Institute on Community Integration Project Staff

Teri Wallace, Project Director

Richard Weatherman, Project Director

Hutchinson Technical College Project Staff

Carol Adams, Training Specialist

Joyce Evenski, Instructor

Veronica Hansen, Instructor

Susan Rosenzweig, Instructor

Andi Upin, Instructor

Written/compiled by Jean E. Ness.

Edited by Dick Sullivan and Vicki Gaylord.

Publication design by Charles Gibbons.

To request additional copies and alternative formats, please contact:

Publications Office

Institute on Community Integration (UAP)

University of Minnesota

150 Pillsbury Drive SE

Minneapolis, Minnesota 55455

612/624-4512

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Introduction

An Introduction to the Series

This series should be useful to paraprofessionals and paraeducators in education as well as direct service staff in community agencies in preparing for a career or in upgrading skills while already employed. Skills needed by individuals working under a variety of titles are often similar. Our focus is on those individuals working in education, but most of the information contained in this series is appropriate for others; please feel free to adapt it where needed.

The Need for Today's Paraprofessionals

The need for paraprofessionals to work with persons who have disabilities has been growing in recent years. Increasing numbers of persons with a range of disabilities are now living in small residential settings in our communities, attending regular classes in neighborhood schools, holding jobs in local businesses, and participating in community recreation and social activities. There is a great need for paraprofessionals to provide the services and supports these individuals need for community living.

By employing paraprofessionals, services for persons with disabilities are able to expand and improve the quality of assistance they provide. Some of the benefits paraprofessionals offer service agencies and consumers are:

- Expanded learning opportunities for persons with disabilities.
- More individualized attention and instruction.
- Increased opportunities for individuals with disabilities to observe and learn appropriate behaviors.
- Increased planning time for educators, supervisors, and others.
- Improved staff morale.
- Better monitoring and evaluation of persons with disabilities.
- Greater consistency in services.
- Improved parent-school relationships.
- Greater involvement of persons with disabilities in education and other settings in the community at large.
- Transportation assistance for individuals with disabilities.
- Vocational skill development for individuals with disabilities.

The Role of Today's Paraprofessional

Paraprofessionals who work with individuals with disabilities have a variety of roles and definitions, depending on the environment in which they work. The Minnesota Department of Education (MN 3525.0200, Subp. 9b) definition states that a program assistant or pupil support assistant provides services to students only

under the direct guidance and direction of a regular or special education teacher or related provider, and those services must be:

- To enhance the instruction provided by the teacher or related staff in academic instruction, physical or behavior management programs, transition, and other integrated activities.
- To supplement instructional activities or to provide extended practice in instances in which the support assistant has had training from a special education or related services staff, and continues to receive ongoing direction and support from a special education teacher.

From the National Resource Center for Paraprofessionals in Special Education and Related Services (City University of New York) comes this definition of a paraprofessional:

A paraprofessional is an employee:

- Whose position is either instructional in nature or who delivers other direct services to individuals and/or their parents.
- Who works under the supervision of a professional staff member who is responsible for the overall management of the program area including the design, implementation and evaluation of instructional programs and the individual's progress.

Paraprofessionals provide services in the following areas:

- Educational programs
- Physical therapy
- Occupational therapy
- Speech therapy
- Recreation programs
- Early intervention and preschool programs
- Social work/case management
- Parent training/child-find programs
- Vocational training programs and job coaching
- Community programs
- Transition

Paraprofessionals are typically different from professionals in the amount of education, certification required for the job, degree of responsibility, and extent of supervision required.

Because the support of paraprofessionals is so essential to the success of individuals with disabilities, this series is dedicated to improving and enhancing skills for paraprofessionals.

About the Series

Whether you have years of experience working with persons who have disabilities or are just beginning, there are probably many

questions you have about the role of a paraprofessional. Some concerns and questions will be very specific to your work setting, while others will be more general. This series, *Strategies for Paraprofessionals Who Support Individuals with Disabilities*, will cover both.

This curriculum is primarily for paraprofessionals who are (or will be) working in educational settings (i.e., special and general education). It will, however, also be useful for those in direct service settings, such as vocational programs and residential settings.

The *Strategies for Paraprofessionals Who Support Individuals with Disabilities* curriculum has four general, or core, training modules and three specialized modules. The core modules, designed for all paraprofessionals, are:

- Module 1: The Paraprofessional: An Introduction
- Module 2: Providing Cross-Cultural Support Services to Individuals with Disabilities and Their Families
- Module 3: Promoting Self Advocacy and Facilitating Friendships and Socialization Skills for Individuals with Disabilities
- Module 4: Positive Behavior Strategies for Paraprofessionals

The three specialized modules that address competencies needed in specific types of service settings are:

- Module 5: Early Childhood: The Role of the Paraprofessional
- Module 6: Working with Individuals Who Are Medically Fragile or Have Physical Disabilities
- Module 7: Transition: The Role of the Paraprofessional

Each module is designed to stand alone, so you may select any one that best meets your needs. However, it's recommended that everyone begin with Module 1 because it provides a basic framework for work as a paraprofessional and for the material covered in all the other modules.

The training you are about to begin will not only address the current reality for paraprofessionals working with individuals with disabilities, but more importantly, the challenges for the future in your career as a paraprofessional. Paraprofessionals aren't expected to have a total understanding of all the concepts in these modules, but the paraprofessional who has a working knowledge of these core concepts will be most effective.

Guiding Principles

Each module emphasizes six basic guiding principles for paraprofessionals working with individuals with disabilities. Those principals include:

- The individual with a disability is the ultimate locus of control and is the most important member in the decision making process.

- The family is the other primary locus of control. Family involvement is essential in any decision making process.
- The team concept is essential in setting up a plan with an individual. This team includes the individual, the family, and all those working with the individual, including the paraprofessional. The paraprofessional is an essential link between what is and what can be for the individual. The best follow-through on any plan comes from teamwork.
- The community should be the basis for all training, as much as possible. This means that, whether offering real-life examples in the classroom or working in real life situations in the community, the focus must be on the most natural setting and support possible. This is essential so the individual can make connections between what is being learned on a daily basis and the real world. This will help the individual generalize the experience to similar situations in his or her life.
- Inclusion is the goal. This means that individuals with disabilities should be included in the mainstream of society – work, school, and recreation. Devotion to such a model will create the most positive results for the individuals and society as a whole. Inclusion suggests that we can and will all benefit by learning to work and live side by side with each other.
- The most effective paraprofessional will be the individual who has a good self-esteem and is able to be assertive. The assertive paraprofessional is able to ask for support and guidance from staff.

About You: The Adult Learner

We know that the adult learner learns differently than younger learners. This training reflects that understanding. In *Strategies for Paraprofessionals Who Support Individuals with Disabilities* we respect these principles about you, the adult learner:

- You are capable and eager to learn new information.
- You have voluntarily given your consent to become a part of this training, and are spending valuable time and money in order to participate.
- You have a rich range of experiences. Therefore you learn best when new information is built upon your past knowledge and experiences. That's why we will do exercises to help you synthesize the old and new information together.
- You come to a new learning situation as a self-reliant learner who has a good idea of how you want and expect to learn.
- Your willingness to learn is based on a combination of outside forces (family, kids, job, etc.) and inside forces (your anxiety, excitement, fears, etc.). All these factors are going to affect your feelings about learning.

- You come into new learning with your own agenda. You know what you want to get out of the training.
- You have set aside time and reorganized priorities to make this learning part of your already-busy life.
- You expect and genuinely appreciate a facilitator or instructor who is well-informed and well-prepared.
- You need to get actively involved in the learning exercises to get the most out of this curriculum.
- You want to apply what you learn to your own situations. That's when it has real meaning for you.
- You need a safe, comfortable environment in which to learn.
- You want to establish networks with others who are also interested in paraprofessional skills.

Because of these facts about you, trainers will:

- Review and ask questions about what you know.
- Respect and view you as a resource.
- Create a comfortable environment.
- Expect you to take responsibility for your own learning.
- Plan opportunities to practice new skills during class.
- Give examples of how to apply information.
- Use a variety of types of instruction.
- Provide ways to evaluate training.
- Use alternate methods to help you understand.
- Give information in a logical sequence.
- Give time for you to share your experiences.
- Give you the chance to get know other paraprofessionals.

After the Training

You will leave this training with more information about paraprofessionals than you had when you started. It's important to remember that no matter how much knowledge you have about your job, the individuals you work with are your greatest trainers. Each one is unique and has his or her own interests and needs. The greatest responsibility you have is to listen to those interests and needs, remember what you have learned, ask what is needed, and use that information in your working relationship and responsibilities.

Therefore, use this training as a basis and build your skills from this point, drawing upon each setting and individual. Whether client, student, teacher, supervisor, principal, director, or superintendent, you will learn from each. With each setting and situation your confidence, ability, and skills will continue to grow. Remember, this training is only as good as the degree to which you use what you learn; seek assistance so you can "do what you know."

Chapter One

1

Changing Roles of Education Related to Students with Disabilities

- 1 Introduction**
- 2 Section 1: Background Information on Health
Impairments in Educational Settings**
- 7 Summary**
- 7 Questions to Ponder**

Introduction

In this module you will read about and discuss many types of medically fragile conditions and physical disabilities. Keep in mind that this module doesn't strive to make the paraprofessional an expert in any area, but instead aims to give an overview of the most common disabling conditions found by the paraprofessional, and basic techniques and care that the paraprofessional – with nursing supervision – should provide.

Advances in health care technology procedures have dramatically increased the survival rates of low birth weight infants, children with chronic illnesses or congenital abnormalities, and survivors of trauma. These survival rates have led to increases in children with health care needs, including those requiring technology assistance.

Before the 1980s, children with long-term special health needs were cared for in hospitals. Today, child advocates support normalization for children with special health care needs, including school attendance in the least restrictive environment. This has changed the school profile and invited new challenges for school staff and increased, in many cases, the responsibilities of the school health care paraprofessional. There are several reasons for these changes. First is the legislation at the state and federal level to deinstitutionalize individuals with disabilities so they might have as normal an environment to live and grow in as possible. Second is that it's much more cost-effective to have individuals with disabilities mainstreamed into society rather than segregated in state institutions. A third reason the changes have taken place is that there has been tremendous pressure from parent and advocacy groups to "normalize" the environments of individuals with disabilities. These advocacy groups believe that individuals with disabilities should be at home and in their neighborhoods whenever possible.

Assigning roles and responsibilities for carrying out special health care procedures has become an issue because of the growing numbers of students with disabilities and special health care needs who are entering school and work environments. Many settings have no set procedures or responsibilities assigned for the often delicate and unique needs of these individuals; thus, the need exists to clarify such staff roles. This module will give background information to paraprofessionals who may find themselves responsible for meeting some or all of those unique individual health care issues. This module only attempts to address these topics in a general way. To really explore all the areas covered here would require much more time and space than allowed here. It's also felt that knowledge beyond this basic background information should be reserved for specific supervision by the nurse on staff and under specific topical training.

Section 1

Background Information on Health Impairments in Educational Settings

Physical Disability

According to Public Law 94-142 (now IDEA) the definition of a physical disability is:

A disorder where severe physical impairment adversely affects the individual's performance. One of the most common causes of physical disability is damage to or the breakdown of the central nervous system – the brain or spinal cord. Individuals with physical disabilities may have mental retardation, learning disabilities, emotional disturbances, speech or language disorders, or special gifts and talents.

"Orthopedic" or "physical" disabilities describe medical or structural conditions serious enough to disrupt the individual's development and require special attention in school, work, or residential settings. Typical examples of orthopedic or physical problems include disabilities present at birth (such as missing limbs, spina bifida, etc.), as well as physical problems resulting from other causes (such as contractures caused by burns or fractures, etc.). In addition, neurological problems may be included in this category.

Health impairments – such as asthma, cardiac conditions, sickle cell anemia, epilepsy, and leukemia – may result in limited strength, vitality, alertness, and affect one's education and work.

One half of one percent (.5%) is the figure usually cited in estimates of school-aged individuals with physical or health impairments. Cerebral palsy accounts for a large part of this percentage, followed by spina bifida.

Characteristics

Physical disabilities can produce a variety of characteristics. Children may experience a wide range of restrictions on their activity, from little or none to a complete restructuring of daily life. The most severely affected individuals may require intensive medical and educational help for which the nurse and health paraprofessional may be called upon to assist. Physical challenges may interfere with an individual's motor functioning, communication, learning skills, or social development.

General Characteristics of Physical Disabilities

Please remember that these are possible characteristics to a very broad category of disability. Not everyone with physical disabilities have all these characteristics. The individual may:

- Have below average motor skills.
- Have jerky or shaky movements.
- Have poor self-esteem in relation to disability challenges.
- Have poor coordination or muscular control.
- Have problems developing good relationships with others.
- Walk slowly or have limited mobility.
- Move around to redistribute weight, if in a wheelchair.

Educational Implications

The contributions of such related services as physical, occupational, and speech and language therapy are often central to the education of individuals with physical disabilities. The greatest progress is achieved when therapy suggestions are consistently applied in the individual's home as well as in school. This carry-over strengthens appropriate feeding, positioning, and language stimulation patterns.

Architectural factors must be considered. Section 504 of the Rehabilitation Act of 1973 requires that programs receiving federal funds make their programs accessible (see Chapter Four for more detail). This could mean structural changes (e.g., adding elevators or ramps) or schedule or location changes (e.g., offering a course on the ground floor). Sometimes the nature of the individual's disability requires changes in school equipment or curriculum. In the same way an individual's placement should be the least restrictive one appropriate for him or her, the day-to-day school pattern also should be as "normal" as possible.

Physical disabilities can have profound effects on one's emotional and social development. To promote growth, parents and teachers should avoid overprotection and encourage individuals to take risks within limits of safety and health. Teachers and peers should also understand that, although individuals with physical disabilities and health impairments may be physically disabled, they are more like their peers than different from them.

Technology holds great promise for making the life of individuals with a disability more "normal". Computerized devices, for example, can help non-vocal, severely physically involved individuals communicate, perhaps for the first time.

Students who require recurrent or long-term hospital care for their condition may need services such as tutoring or home bound instruction to keep up with their academic requirements. Depending upon the nature and severity of the condition, counseling for the family may be helpful.

Tips for Working with Individuals with Physical Disabilities

- Make sure working or teaching areas are physically accessible.
- Arrange the environment, if necessary, to accommodate the individual's wheelchair or other mobility needs.
- Consider emergency evacuation and what alternatives would be necessary for the individual. Then acquaint the individual with the procedure he or she should follow.
- Don't isolate the individual in a seating arrangement because of mobility needs, but include the individual into the setting while still giving him or her accessible seating.
- Support the need of the individual to have the necessary time to get from one location to another without the hassle of crowds, whenever possible.
- Arrange a peer partner for the individual in situations where it would be the easiest and most logical support.
- Encourage the accommodation of extra time for the individual to complete written tasks.
- Work out necessary adaptations in the setting with the individual and supervisor or teacher to meet specific needs.
- Support accommodations such as giving answers into a tape recorder or giving answers if he or she cannot write.
- Be honest with the others in the setting by letting them know how they can and cannot help the individual who is physically disabled.
- Additional tips:

Adapted from a fact sheet produced by National Information Center for Children and Youth with Disabilities: Washington, DC.

Other Health Impairments

Health impaired is a term commonly used for someone who has chronic health challenges or is medically fragile. Health impaired, as defined by Public Law 94-142 (now IDEA), refers to an individual who has limited strength, vitality or alertness, due to chronic or acute health problems such as heart condition, tuberculosis, rheumatic fever, nephritis, asthma, sickle cell anemia, hemophilia, epilepsy, lead poisoning, leukemia, cancer, diabetes, or acquired immune deficiency syndrome (AIDS), which adversely affects an individual's ability to perform.

Characteristics of People with Health Impairments

Remember that these are possible characteristics, but, of course, not all people with health impairments have all of these characteristics. This is just a guideline to give you an understanding of the possible characteristics involved. The individual may:

- Display such defense mechanisms as denial, withdrawal, depression, anxiety, hostility.
- Show over-dependence on parents and family members.
- Have economic difficulty due to extended illness.
- Have transportation difficulty.
- Appear to have limited friends.
- Have poor attendance (health related).
- Appear inattentive or listless.
- Tire easily.
- Appear to have low self-esteem.
- Need to rest frequently.
- Have limited mobility depending on his or her illness.

Tips for Working with Individuals with Health Impairments

- Be part of the planning team or ask your supervisor about any health issues you need to be aware of when working with an individual.
- Offer suggestions and observations in planning for the individual to help accommodate absences. This way the individual can attempt to keep up, even if there are extended periods at home or in the hospital.
- Understand that the individual's expectations and reasons for attending and participating in your setting may be different from others. Participate in sessions that ask the individual and his or her family about personal and family goals for attending your setting.
- Offer the individual an atmosphere of acceptance: make arrangements if she or he needs frequent breaks to rest.
- Arrange the environment in a way that best accommodates access to whatever facilities he or she needs (bathroom, hallways, work station, etc.).
- Find out what special equipment is needed to provide reasonable accommodations. Work with the individual's planning team and family.
- Allow individual to work at his or her own pace.
- Make audio or video tapes of activities so the individual can use these when absent.
- Help to determine what the reasonable accommodations are

for the individual encourage the individual to practice using these accommodations.

- Additional tips:

Gathering Health Needs Information

The school nurse should have had an opportunity to assess a student and his or her family's needs prior to or immediately at school entrance. Such information is used by all school staff who work with students.

The following is a sample form which may be helpful to use when meeting with individuals for the first time to determine their health needs in your environment. It contains the kind of information you may want to share with the school nurse. You may also want to use this in addition to the health information collected on the health record.

Student name _____ Date _____

School/work site _____

Grade/Age _____ Advisor _____

- 1 What is the nature of your medical condition/disability?

- 2 How long have you had this condition?

- 3 How long do you feel you will need support from our office for specific needs you may have?

- 4 Do you know how to ask for what you need?

- 5 What specifically do you need help with during the school/work day?

6 What equipment do you use or need?

7 Do you need assistance with them during the day? If so, what type of assistance? When?

8 Do you have any special concerns or personal needs that I should know about and can support you in? (Is there anything else I should know?)

9 Other comments or observations (*Date your comments.*)

Summary

Children who have physical disabilities or other chronic health conditions are attending school, and they participate like their other classmates do in their regular classroom. Sometimes these children have physical needs that they need assistance to perform. Definitions have been established to differentiate these students in order that their individual needs can be met.

Questions to Ponder

- What's your experience in working with students who have physical disabilities or other chronic health conditions?
- How would you differentiate between students with physical disabilities and students with other chronic health conditions?
- What implications of IDEA have you seen or experienced in your school?

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Chapter Two

Demographics & Disabilities

9 Introduction

9 Section 1 National Demographics Related to
Disability

11 Summary

11 Questions to Ponder

Introduction

In preparing to work with individuals with disabilities in general, and especially those with special care needs, it's helpful to have background data on just how many people in the United States have disabilities. It's also helpful information to know how many people with disabilities are working in communities. This information adds to your perspective about the value of supporting individuals with disabilities in your school, work, or residential setting. It lends credibility to value of supporting the preparation of individuals with disabilities for post-secondary schools and work settings. The following facts are presented to you as background information from a national perspective.

Section 1

National Demographics Related to Disability

According to the Americans with Disabilities Act of 1990, there are 43 million Americans with disabilities.

Although there are many ways of calculating these numbers, the President's Committee has calculated the following data which was published by The National Center for Medical Rehabilitation Research in "The Scope of Physical Disability in America - Populations Served":

- People with hearing impairments:
22 million, including 2 million who are deaf
- People who are totally blind:
120,000
- People who are legally blind:
60,000
- People with epilepsy:
2 million (Note that four out of five people with epilepsy don't have seizures because they take medication.)
- People who are partially or completely paralyzed:
1.2 million
- People who use wheelchairs:
1 million
- People with developmental disabilities such as cerebral palsy and mental retardation:
9.2 million

- People with speech impairments:
2.1 million
- People with mental retardation:
2–2.5 million people. Nine out of ten people with mental retardation have mild mental retardation.
- According to the National Institute on Mental Health, there are five million people with mental illness.

Work Force Data on Individuals with Disabilities

In 1989, the Census Bureau reported the following work-force data about persons with disabilities in the work-force in a report entitled *Labor Force Status and Other Characteristics of Persons with a Work Disability: 1981–1988*.

- 13.4 million people ages 16 to 64 report a work-related disability. That's 8.6% or about one in every twelve Americans with disabilities.
- 31.6% of people with disabilities work or actively seek work.
- 78.6% of Americans without disabilities work or actively seek work.
- Participation in the labor force of men with disabilities (working or actively seeking work) has dropped from 41.9% in 1981 to 35.7% in 1989. However, among women with disabilities, it has risen to 27.5% from 23.7%.
- One in three severely disabled adults is black or of Hispanic origin, compared to just over one in five in 1982.
- Adults with disabilities are almost four times as likely as are non-disabled adults to have less than a ninth grade education.
- According to a Harris Poll taken in 1986, two out of three people with disabilities aren't working. And of those, two out of three want to work.

Reactions of Employers to Workers with Disabilities

The following is data from over nine hundred managers interviewed by the Harris Poll who have people with disabilities working for them:

- Nineteen out of twenty managers give employees with disabilities a "good" or "excellent" rating on their job performance. They say employees with disabilities work as hard or harder than employees who don't have disabilities.
- Thirty-nine percent of line managers rate employees with disabilities as better on attendance and punctuality than non-disabled employees, and forty percent rate them about the same.
- The average cost of hiring a person with disabilities is the same

as hiring a person without a disability, according to three quarters of the employers surveyed.

- Only 43% of EEO officers say that their companies have hired people with disabilities.
- Three out of every four managers say that people with disabilities often encounter discrimination from employers.

This information was taken from a report written by the President's Committee on Employment of People with Disabilities: Washington, DC.

Summary

With the onset of the American with Disabilities Act (ADA) and IDEA, people with disabilities are expecting reasonable accommodations at school, work, recreation, and employment and inclusion in classrooms. In examining demographics it can be demonstrated that many people live with disabilities in the U.S. – a number that is increasing – and that people with disabilities are productive, capable citizens.

Questions to Ponder

- What's your experience in working with people who have disabilities or a chronic health condition?
- If you have a disability, what expectations would you have for education, recreation, or work?
- How do the ADA and IDEA make a difference in your life?

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Chapter Three

Inclusive Language

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- 13 Section 1 Etiquette & Disabilities**
- 16 Section 2 Inclusive Language**
- 17 Summary**
- 17 Questions to Ponder**

Introduction

In your position as a health paraprofessional or general paraprofessional, you will probably be put into situations with little or no explanation about what the appropriate etiquette is for dealing with an individual's unique disability needs. These are brief tips and ideas for using appropriate etiquette with people with disabilities which can help prepare you for those occasions.

Section 1

Etiquette and Disabilities

The best course of action for the paraprofessional is always to ask individuals what they need from you or what you can do to assist them. Never assume you know what's best for the individual without first asking; doing so would take away the individual's rights and integrity. Some general tips to provide you with some background suggestions are listed below.

How do we learn to be comfortable around people who are different from us? How do we know the right thing to do to be helpful, but not patronizing or condescending? For many of us, our first exposure to disabilities came through a family experience, either through permanent or temporary disability, during or after an illness. It has been said that aging, in and of itself, is synonymous with disability: as we age, we begin to confront the fragility of life. In this sense, most of us will come to terms with our own disabilities, our own fragility, at some point. It isn't uncommon to feel uneasy around a person with a disability especially when there has been not prior experience or awareness.

Whatever the exposure to persons with disabilities, one's comfort can be increased by an awareness of what is and isn't expected or appreciated. The following points are designed to increase one's awareness and comfort with persons with disabilities.

General Suggestions

- Remember that people with disabilities are more "similar to" than "different from" other people. Build on interests the individual shares with others without focusing on differences.
- Don't develop preconceived notions about what the individual can or can't do. Be as friendly as you would be with any other person. Let the individual take the initiative to explain the disability, limitations, and accommodations or modifications needed; if the individual doesn't take the initiative, then you should ask.

- Be consistent in what behavior you expect of everyone with whom you work. Don't accept inappropriate behavior from someone with a disability just because he or she has a disability. This will only make the person less self-sufficient because socially inappropriate behaviors would not be accepted in work or social settings.
- Always ask if the individual needs assistance. Don't assume he or she needs help and jump in. The best rule of thumb is to let the individual know they can ask and receive help at any time and then let the individual take the lead.
- Be patient. Let the individual learn and progress at his or her own rate. However frustrated you as the paraprofessional become, it probably doesn't hold a candle to the frustration experienced by the individual with a disability.
- Let the person with a disability take risks: that's the best way to learn about personal potential. Be sure safety precautions have been taken, but don't over-protect the individual.
- Be a role model for non-disabled people by showing appropriate behavior toward the individuals you work with who have disabilities.
- When in public, if a child asks questions about a person they see with disabilities, answer directly and promptly. The person with the disability may often be willing to answer the question for the child.

Specific Suggestions for Individuals with Any Disability

- If the person doesn't speak clearly, don't be afraid to ask the him or her to repeat, even several times if necessary.
- Don't be afraid to laugh with the person.
- Give help only when it's requested. Sometimes offering (if the individual falls, for example) may be appropriate, but never assume assistance is wanted. Let the person explain the specific help he or she needs.
- Don't stare at a person with disabilities but at the same time don't ignore his or her existence.
- Talk directly to the person with the disability, not to the wheelchair or the interpreter, for example.
- Don't patronize a person with a disability by complimenting him or her for something undeserved.
- Don't be afraid to use phrases like "see you later" to a person who is blind or "I haven't heard from you" to a person who is hearing impaired. They usually aren't considered offensive to people with a disability – they may use these phrases too.

Specific Suggestions for Individuals with Visual Impairments

- Identify yourself when entering the presence of a person who is blind.
- When walking with a person who is blind, let the person take your arm and walk a little ahead. Never grab the person's arm.
- Ignore the "service dog" of a person who is visually impaired. The dog is trained to serve and is working. Don't distract the animal.
- Offer information about the immediate surroundings to an individual who is visually impaired. For example, tell the person there's a "construction ahead" sign while walking together, but wait to be asked to offer any further assistance.
- Control noise for a person who is visually impaired because the person compensates for the vision loss by using acute auditory skills.

Specific Suggestions for Individuals with Physical Impairments

- Address the individual in a wheelchair at eye level.
- Don't take control of the individual's wheelchair without first asking or being asked.

Specific Suggestions for Individuals with Hearing Impairments

- Speak directly to an individual who is hard of hearing regardless of whether or not an interpreter is present.
- Ask the individual if he or she understood information given, if you are uncertain or if the person appears unclear.
- Control the environment to keep it as quiet as possible.
- Ask the individual's permission before introducing him or her as hard of hearing.

Section 2

Inclusive Language

Language is a very powerful form of communication. The way people are addressed, written about, and spoken to sends a strong message about how they are valued. In the recent past, the disabilities community has made strong efforts to change the ways people speak and write about persons with disabilities. Putting the *person*

first and not the disability (i.e. a person with epilepsy, not an epileptic person) sends the subtle but strong message that the person is of primary importance, and his or her disability is secondary. Because you may be in a position to write reports about a person's condition or because you may attend meetings in which you are called on to speak about an individual's condition, it is critically important that you be aware of the appropriate language to use. The following is designed to give you some ideas about how to speak and write when referring to people with disabilities.

When speaking and writing about an individual with a disability, *always* put the person first, the disability second. For example one would say,

- "Student with a learning disability,"
- "Person with cerebral palsy,"
- "Individual who uses a wheelchair," *or*
- "Consumer who has a physical disability."

Use the word *disability* to describe a functional limitation, for example, "Carla has a physical disability which affects her ability to stand for long periods of time" or "Craig has a visual disability and will need special lighting in his work area."

Use the word *handicap* to describe a situation or barrier created by society, the environment, or individuals themselves, for example, "The curb created a handicap for John in his wheelchair," or "The staircase on the outside of the courthouse was a handicap for Norman with his crutches."

Other Tips

- Introduce someone with a disability as you would anyone else. Don't refer to the disability as part of the definition: use his or her name.
- Don't patronize a person with a disability by praising more than would be customary for any student.
- Let the person ask for what she or he needs or describe his or her disability, if and when he or she feels comfortable doing so.
- Say *able-bodied* or *non-disabled* instead of *normal* when referring to someone without a disability as such.
- Avoid pity or pity statements. Avoid terms like *crippled*, *mute*, *deaf and dumb*, or *afflicted*. For example, when talking about someone who has had a heart attack, refer to him or her as a heart attack *survivor* rather than as a heart attack *victim*.
- Don't sensationalize a disability by writing or talking about it if it doesn't bear on the point of the discussion or story.

Summary

How we relate to one another can be easily taken for granted when we don't have a disability or other health conditions. Courtesy and respect are aspects of relationships we expect to receive from and give to others. At times, people with disabilities or chronic health conditions are treated as objects, their needs or wishes are ignored, or are done "to" or "for" rather than "with". It's essential that we all remember to care or work with others as we like to be cared for or worked with. The "golden rule" is the foundation of all our relationships.

Questions to Ponder

- Reflect on a situation you experienced in relation to someone with a disability or chronic health condition. How would you "re-do" the situation if you had the opportunity?
- If your child had a disability or chronic health condition, how would you deal with people who stare or point at the two of you? How would you feel? List strategies you can use to increase your comfort level in relations with students who have disabilities or chronic health conditions.

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Chapter Four

Education & Health Laws

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- 19 Section 1 Disability-Related Laws
- 22 Section 2 Laws Relating to Abuse and Neglect
- 24 Summary
- 24 Questions to Ponder

Introduction

Individuals with disabilities and their families are protected under several laws. It's important for individuals with disabilities to understand this and know what laws may apply to them and the rights they have in a particular situation, whether it be employment, school, or living. Therefore, examples of laws have been added to this section on rights so you, as a paraprofessional, have a basic understanding of what some of the laws are affecting the rights of individuals with disabilities.

Section 1

Disability-Related Laws

The following are examples of laws that affect individuals with disabilities. This is not meant to be an all-inclusive list; however these are the laws most often referred to in schools and in residential and work settings.

The Americans with Disabilities Act

The most recent law affecting individuals with disabilities is the Americans with Disabilities Act of 1990 (ADA). Read the Fact Sheet from the U.S. Department of Justice (found in Appendix C) to give you a better background of the law and its implications.

Section 504 of the Rehabilitation Act of 1973

As part of the Rehabilitation Act of 1973 (Public Law 93-112) Congress enacted Section 504, the first federal civil rights law protecting the rights of individuals with disabilities. Section 504 provides that, "no otherwise qualified handicapped individual in the United States... shall, solely by reason of... handicap, be excluded from the participation in, be denied the benefits of, or be subjected to discrimination under any program or activity receiving Federal financial assistance."

This law applies to state and local agencies and governments if they receive any federal money.

This law protects any person with a disability who is "otherwise qualified", just like ADA. That means the person with the disability must be able to perform the necessary tasks (with accommodations and modifications if needed) in spite of the disability. This means, if the disability doesn't prevent the individual from doing an adequate performance on the job, he or she is entitled to the job and cannot, under federal law, be denied the job. For example,

a person who is mildly retarded who can pass the driver's license test is entitled to be hired to drive the school van because he or she has proven the ability to perform the necessary tasks in spite of the disability.

Section 504 also applied to school. If a student is in need of accommodations or modifications to learn, they are entitled to reasonable accommodations. For example, a person who uses a wheelchair may enroll in a community college and find that the department he or she needs to access doesn't have a ramp or elevator. The school must accommodate that student to access the information. They may do that by relocating the class or lab, or by putting in an elevator or curb cuts. Students who may have learning disabilities are entitled to readers, note-takers, books on tape, or other accommodations to facilitate their learning under Section 504.

Section 504 came long before ADA but has been recently updated and still covers some situations that ADA may not. For further information about Section 504 of the Rehabilitation Act, refer to the Fact Sheet in Appendix D.

Individuals with Disabilities Education Act (IDEA)

IDEA is a federal law (Public Law 101-476) which was formerly called the Education for All Handicapped Children Act (Public Law 94-142). There are certain minimum standards all states must comply with under IDEA and then each state can add to that compliance with additional statutes. Minnesota Chapter 3525 and Minnesota Laws on Special Education along with IDEA spell out the rights of parents for their children in special education. Some of these rights include the right to:

- To agree or disagree to the school's request to test the child.
- To have the child given a test that is not discriminatory based on race or disability once agreement to assessment is given.
- To receive a written copy of the assessment results.
- To have assessment results explained thoroughly.
- To have an independent evaluation if parents disagree with the school's assessment, in which case the school must pay for the evaluation unless, through a due process hearing, the evaluation given by the school is determined to be appropriate.
- To have parents as equal members of the student's planning team that decides if the student needs special education and if so, to what extent.
- To have someone accompany parents to the Individualized Education Plan (IEP) conference.
- To agree or disagree with the action suggested by the school.

Public Law 99-457 (Part H of IDEA)

This federal law requires schools to serve young children with disabilities beginning at birth. The Individual Family Service Plan (IFSP) is the written document, like the IEP, for this law. In this plan, the needs of children are planned from birth to the age of three. Minnesota has developed an IFSP plan. As of the fall of 1993, all services described in the IFSP (by all the agencies involved) must be implemented.

Material on IDEA adapted with permission from PACER Center, Inc., 4826 Chicago Ave. S, Minneapolis, MN 55417. Telephone: 612/827-2966

**Minnesota Rule 3525.2925:
Use of Behavioral Intervention with Pupils**

As another example of Minnesota laws that provide rights to individuals with disabilities, the Behavioral Intervention Procedures for Students with Disabilities is included in this section. This law is specifically directed to rules governing the discipline procedures used with students in school who have disabilities.

In 1989, the Minnesota State Board of Education was directed by the Legislature to adopt rules governing the use of aversive and deprivation procedures for pupils with disabilities. The Board was asked to draft rules which promote the use of positive behavioral interventions, and to ensure that aversive or deprivation procedures, when appropriate for a student, are included in that student's Individual Education Plan (IEP). The rule, which went into effect in January 1992, is intended to encourage the use of positive approaches to modify students' behavior.

Three categories of behavioral interventions are listed in Minnesota's Proposed Permanent Rule for Use of Behavioral Interventions with Pupils Who Have Disabilities. They are *exempted procedures*, *prohibited procedures*, and *regulated procedures*. These three categories are described in detail in Module 5, *Positive Behavior Strategies for Paraprofessionals*.

Each school district is to revise district policies, where necessary, and to provide any necessary staff development to appropriately implement the new rule. Each district should distribute their written discipline policy during IEP meetings, and review common practices in terms of appropriateness for a particular student.

Section 2

Laws Relating to Abuse and Neglect

It's important to understand some basic laws that apply to your work with individuals who may be subject to abuse and/or neglect. This is just a brief description of some basic information about key laws you should know.

The Vulnerable Adults Act

This is a law in Minnesota that requires all people in licensed occupations, and others, to report abuse and neglect of a group of citizens known as vulnerable adults. These people include individuals with mental and physical disabilities, the elderly, or other adults who cannot protect themselves. The reporting of abuse or neglect of these individuals should be made directly to your supervisor if you suspect any condition that is not healthy or safe for individuals. If you suspect your supervisor or institution of abuse or neglect, you should report incidences to legal authorities.

The Child Abuse Prevention Act

Neglect of children is defined in two places in Minnesota state law. Anyone can report abuse or neglect. However under legal mandate the following people are required to report any suspected incident of child abuse: a professional or the professional's delegate who is engaged in the practice of healing arts, social services, hospital administration, psychological or psychiatric treatment, child care, education, law enforcement, or a member of the clergy. A list of mandated reporters would be physicians, dentists, educators, day care staff, group home staff, therapists, clergy, foster parents, pharmacists, social workers, guardians *ad litem*, and nurses. Paraprofessionals fall into this category and are mandated by state law to report any suspected cases of child abuse. Anyone who reports child abuse or neglect in good faith is immune from any civil or criminal liability. The reporter's name is confidential, accessible only upon consent of the reporter or by court order.

Other Pertinent Minnesota Laws

MS 123.7

This law requires that students be immunized against certain diseases. Student need to show proof that they have had these immunizations when they enter school.

MS 116.75-.83

This law regulates certain contagious diseases by requiring that they be reported to the Minnesota Department of Health. Schools make informal reports about these contagious diseases.

MS 148.17-.285

This is the Nurse Practice Act (see a complete copy of the act in Appendix G). This law describes the relationship of the licensed school nurse (LSN) and other school personnel such as the school health paraprofessional (SHP). The LSN may delegate duties to the school health paraprofessional and is legally responsible for supervising the school health paraprofessional.

MS 123.35

This law states that school districts which have a thousand students or more (preschool through grade twelve) are required to have a licensed school nurse. Schools are to assess the basic health needs of students.

MS 13

This is the Minnesota Government Data Practices Act. This describes how student records are to be kept and what kind of information can be shared about students. This Act states that a release of information must be signed by parent or guardian (or students age eighteen or older) in order to share information about the student.

MS 126.202

This law sets policy for how each school is to establish medication administration. Schools must know these policies and then set their own rules within those policies.

MS 626.556

This is the Maltreatment of Minors Act. It requires that school health paraprofessionals, because they have been delegated by the licensed school nurse, are mandated to report abuse and/or neglect of students.

MS 144.29

Each school must create a permanent public health record to be kept for each child of school age.

Summary

Schools follow numerous federal and state legislative mandates when meeting the educational needs of students. These laws exist to guarantee that all students have the same educational opportunities and the same opportunities to learn. Many of these mandates are especially pertinent to the special education programs, but everyone needs to be aware of them and how these mandates may directly or indirectly effect their experiences at school.

Questions to Ponder

- How does IDEA impact you as you work at school?
- Why are you a mandated reporter?
- The Minnesota statutes relating to health at school are developed from the basic premise that children who are well learn better. How does this idea impact you in your job at school?

5

Chapter Five

Delegation of Responsibilities

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- 25 Section 1 The Role of the School Nurse
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Introduction

In order for the school health paraprofessional to understand who is responsible for what in the school, it's important to understand the role of the school nurse. She or he will be the paraprofessional's immediate supervisor and the who will give direction and responsibilities to the paraprofessional. Therefore, this section has been added to give you an understanding of the responsibilities of the school nurse.

Section 1

The Role of the School Nurse

Schools now educate and care for individuals with health needs that are extensive in nature, require sophisticated intervention, and often exceed the capabilities of school personnel. These increasing health care demands, coupled with shortages of school nurses, require formal partnerships among all levels of school personnel to provide for the care and well-being of those students with medically fragile conditions. The formation of these health care teams of primarily non-medical personnel raises additional levels of responsibility for the school nurse.

The role of the school nurse in the care of students is to assess the health needs of the child in the school setting and to coordinate with staff, family, physician and community agencies to provide a comprehensive school health program that facilitates the maximum educational opportunity for the individual. This responsibility has escalated dramatically over the past sixteen years with the inclusion of more and more individuals with medically fragile conditions in the school system.

Each state establishes its own health screening criteria for students. These requirements range from minimal to comprehensive. But no matter what the criteria, the school nurse follows certain standards of practice in fulfilling his or her responsibility to the student. Standards of practice for the school nurse have been developed by a task force of organizations, including the National Association of School Nurses (NASN). These standards serve to ensure high quality, comprehensive care for students, as well as to guide the school nurse in daily activities and planning. These standards include the following:

- Application of appropriate theory as the basis for decision making in nursing practice.

- Establishment and maintenance of a comprehensive school health program.
- Development of individualized health (care) plans.
- Collaboration with other members of the school health team in assessing, planning, implementing and evaluating programs and school health activities.
- Promotion of optimal levels of wellness in students, their families and others through health education.
- Participation in continuing education, peer review, and activities to maintain professional development and excellence.
- Participation with others in the community to provide a continuum of the process to promote healthy life-styles and disease prevention.

Roles and Responsibilities of the School Nurse

The role of the school nurse in working with school personnel is to determine the orientation, education, and training necessary to enable them to participate in a safe and appropriate manner in meeting the health needs of the individuals who has a medically fragile condition. The school nurse is ultimately responsible for training the health paraprofessional on site. School personnel, by and large, have no training in health-related fields. Moreover, most had never anticipated ever having to perform health care procedures when they prepared to become teachers or school employees. Many have also struggled with their anxieties over this additional responsibility as they work to provide high standards of education for students. Since school staff are with the students the majority of the day and are the primary caretakers, it's imperative that all members of the team are trained to participate in appropriate procedures/activities and know when to get the school nurse or secure emergency assistance.

The school nurse has a responsibility to help team members understand both their capabilities as well as their limitations in participating in the health care process. A large part of this understanding needs to be based on a basic knowledge of the state Nurse Practice Act (see Appendix G) regarding delegation. The Nurse Practice Act describes and states that the professional nurse (not the licensed practical nurse) is authorized to delegate independent nursing functions and delegate medical functions to other medical personnel. It clearly states the responsibilities of delegation. Beyond that, the school nurse needs to assess student needs, determine how the staff can participate in meeting those needs, and then develop a training program and resource material to satisfy those goals.

In order to ensure that this is accomplished, the following recommendations were made in 1992 by the American Federation of Teachers to the school:

- Develop a procedure or policy manual and update it regularly.
- Establish a uniform recording system, with standardized forms, for use by all staff.
- Train staff on (appropriate) procedures and routinely assess individuals' ability to perform those procedures safely.
- Keep a documented list of trained staff, when they were trained, and an assessment of their capabilities.
- Develop emergency procedures/evacuation plans and train and evaluate staff in these areas.
- Arrange for or provide inservice training on basic first aid and CPR training.
- Arrange for or provide inservice training on medication administration, when appropriate.
- Arrange for or provide inservice programs on current health issues.
- Arrange for or provide inservice programs on universal precautions and the appropriate disposal of contaminated waste.

Legal Considerations for the School Nurse

As the nurse well knows, each state has its own nurse practice act governing the scope of practice for the nurse and may limit those nursing tasks that can be delegated to an unlicensed person. When the school nurse has responsibility for several different facilities or is not present at the school site, he or she still maintains responsibility and liability for care delivered. Ensuring that care is appropriately delegated, within the requirements of both the Nurse Practice Act and school administration policy is critical.

Many nurses are unaware of the extent of their liability in these situations, and equally as many struggle with vague language in state laws describing what can be delegated and to whom. Experts recommend that the nurse become as familiar as possible with administration policies that may exist regarding this, but most important know the law. The following four points, delineated in a journal article in *Nursing '89*, can serve as guidelines in helping the nurse determine appropriate delegation.

- **Safety:** Student safety must be the primary concern at all times. If there is concern that the complexity of the task endangers student safety if not handled by an individual with advanced skills, don't delegate.
- **Staffing:** Don't let short staffing predicate who gets a particular assignment or "fills in" in a pinch. Know the skill level and capabilities of all team members to determine who can best do the job. If no one else is capable, don't delegate.
- **Schooling:** Consider all the educational components in a person's background, including inservicing and experience,

before asking them to participate in specific procedures. Make certain you've observed and, if necessary, corrected technique; if not, don't delegate.

- **Supervision:** The keys to safe delegation are adequate supervision and being available should questions or problems arise. If you can't be sure of either, don't delegate.

Adapted with permission from *The Medically Fragile Child In The School Setting: a Resource Guide for the Educational Team*. American Federation of Teacher's Ad Hoc Committee on Health Care Responsibilities in Special Education, 1992.

Section 2

Planning for Safe Delegation

These are tips for the school nurse to follow because he or she is ultimately responsible for what happens in the health office. These are good, however, for you as the paraprofessional to be aware of because you may find yourself in a position to delegate some responsibilities on a daily basis.

Your professional judgment of the school nurse is tested routinely in the course of every working day. Yet, when it comes to delegation of duty, the combination of high acuity and low staffing patterns place a strain on even the most experienced professional's judgment. Even so, it's up to the school nurse to remember that the patient, his or her task, responsibility, and license are all "on the line" when they delegate authority, because, while a school nurse may delegate authority, he or she cannot delegate responsibility.

Before a school nurse delegates, he or she should be sure to be familiar with the state's Nurse Practice Act (which is found in Appendix G of this module) and any institutional policies regarding delegation at your place of employment. In some states, the Nurse Practice Act doesn't allow a registered nurse to delegate professional tasks regardless of the education or experience of the licensed practical nurse or nursing assistant to whom the tasks would be delegated. Some institutions limit which professional tasks can be delegated. On the other hand, some institutions attempt to circumvent the nurse and inappropriately assign tasks to institutionally trained personnel.

When delegating, the school nurse needs to ensure that the person to whom he or she is transferring duties not only has the capacity to do the work but is also proficient at it. The nurse, like the paraprofessional, is responsible for the care of patients and has the final word in determining to whom he or she will delegate

nursing tasks. No one else can make that determination.

There are four factors the school nurse should consider when delegating authority:

Evaluate

- The patient's status and needs before determining whether tasks related to care can safely be delegated.
- Staff with whom the school nurse is working. (You should assign duties to licensed personnel before considering others).
- The training and general competence of the person to whom the nurse would delegate.

Educate

- The patient about the fact that some care will be administered by a co-worker in whom the nurse has confidence and whose work the nurse will supervise.
- The person you've chosen about the patient's needs, treatment, and care program, and both explain and demonstrate procedures.
- The nurse's designee about expected outcomes (You should also talk about what circumstances would require your additional help.)

Communicate

- Confidence in the paraprofessional chosen to perform the nursing task(s).
- Expectations for performance and limits on intervention.
- The nurse's receptiveness to discuss any concern, questions or hesitancy about performance of the task.

Supervise

- Directly any co-worker whose skill level the nurse has concerns about, or who is performing the task for the first time (This should be documented.).
- Periodically to reevaluate skills and ensure excellence.
- First and foremost, the school nurse should be available to co-workers and staff.

Adapted with permission from Federation of Nurses and Health Professionals AFT/AFL-CIO: Washington, DC.

Roles and Responsibilities

Write in the name and, if appropriate, the date for each responsibility below.

	School Nurse	Health Para
Medication Administration	_____	_____
Record Keeping	_____	_____
Establishing Emergency Procedures	_____	_____
Following Emergency Procedures	_____	_____
CPR, First Aid Training Completed	_____	_____
Safety Issues Addressed	_____	_____

Section 3

Job Description for the Health Paraprofessional

The school supplements the work of the licensed school nurse (LSN) through the employment of the school health paraprofessional (SHP). In this way the school is able to provide more comprehensive health service to a greater number of students.

The school health paraprofessional is a carefully selected individual who has pre-service training that qualifies him or her to function in some of the routine tasks related to the school health service program. The SHP is an unlicensed auxiliary worker with special technical needs.

Job Responsibilities

- The SHP performs services within the school health program under supervision and according to written policies and procedures adopted by the school board and its administration.
- The SHP maintains confidentiality of information learned or received on the job about students and their families.
- The SHP functions with the knowledge and acceptance of the limits of the position.

Relationship to Others

- The SHP receives administrative supervision from the school superintendent, or his designated representative. The SHP receives guidance and direction on health related functions from the LSN.
- The SHP fosters communication between the LSN, the students, the parents, and school personnel for information and request for health service.
- Under the LSN's direction, the SHP assists in recruitment, orientation, and direction of parents/volunteers for school screening programs.
- The SHP's role in meeting the personal care needs of the individual will depend on the degree of the disabling condition, the length of time the person has had the disability, and the stability of the condition.

Content of the Job and Example of Work

- Gives first aid and emergency care as provided for in the school's first aid and emergency care policies.

- Participates in screening programs
- Assists in organization of the program
- Performs routine screening procedures
- Assists in training and coordinating use of volunteers according to school policy
- Makes appropriate referrals to the LSN or county public health nurse for follow up of student health problems, and records appropriate information on the public health records.
- Keeps reports for the LSN or county public health nurse for review and possible follow up of student health problems.
- Performs clerical details related to pupil health records, reports, filing, telephoning, ordering and checking supplies and equipment.
- Assists in organizing and participates in:
 - Immunization program
 - Dental program
 - Early childhood screening
- Participates in school injury prevention programs.
- Maintains health room or office.

Qualifications

Academic

- High school diploma
- Clerical skills
- Red Cross Advanced First Aid certificate and CPR
- Demonstrated skills in vision, hearing, and scoliosis screening

Personal

- Ability to maintain positive working relationships with school personnel and the community
- Ability to recognize limitations and to accept and utilize supervision and direction.
- Interest in working with students

Questions to Ask about a Health Paraprofessional Position

Interview a school health nurse and then answer these questions.

- 1 What will my daily duties be?

2 How flexible do you expect me to be with my hours or routine?

3 Who's my immediate supervisor if you aren't in the building?

4 If there's an emergency and you aren't in the building, what procedure should I follow? (Is it posted?)

5 Do individuals with special conditions have individualized health care plans? If so, where are they kept? Do I have access to them?

6 Who are the other members on the health team with whom I will be working?

7 What sort of contact or communication am I expected/allowed to have with parents?

8 Other than health care duties, what other duties are expected of me? (clerical, record keeping, clean up, individual's specific needs, etc.)

9 Do you require that I have CPR and/or First Aid Training? If so, will you pay for the training? How often is the training required?

10 Throughout the building, what other duties do you foresee that I will have?

11 Other questions or comments:

My Health Paraprofessional Job Description

After interviewing a school health nurse and completing the "Questions to Ask about a Heath Paraprofessional Position" and reading the "Sample Job Description" and other readings about expectations of the health paraprofessional, create your own job description below.

- **Health Related Responsibilities**

- **Clerical Responsibilities**

- **Communication Responsibilities (written and oral)**

- **Emergency Procedures I must follow**

- Other Responsibilities
-
-
-

Summary

For students with special needs, the licensed school nurse (LSN) is often a member of the team for developing, reviewing, and revising the Individual Education Plan (IEP) for students. When the student has special health needs, he or she is an integral part of this team and, with input from the student and family, develops an Individual Health Plan (IHP) and an Emergency Care Plan (ECP). Students who require a paraprofessional to assist them with their health issues, the school health paraprofessional (SHP) works with the LSN. By MN statute, the LSN can delegate some of his or her nursing tasks to the paraprofessional. The nurse is responsible for how the paraprofessional performs these tasks – in essence, he or she works under the nurse's license.

Questions to Ponder

- What relationship do you have with the LSN in your school?
- When the LSN delegates nursing tasks, he or she considers certain criteria. What are they?
- Why is your job description important? What input did you have (or would like to have had) in the development of it?

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Chapter Six

Communication

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Introduction

Communication is the exchange of information between two or more people. The biggest issues in communication are that people:

- Do not communicate clearly.
- Do not communicate often enough.
- Forget to communicate with all parties involved.
- Do not really listen to each other.

How you communicate with the staff you work with is essential in being a good team member. Effective communication is crucial to the success of a workable relationship between a paraprofessional and other staff members. When in doubt, communicate.

Section 1

Basic Strategies for Clear Communication

Here are some tips to remember when trying to pay attention to positive communication:

- Active listeners make good communicators. Active listeners have positive attitudes and open minds. By using non-verbal cues, good eye contact, and remembering what was said, they show interest in what the other person is saying.
- The attitudes and feelings of both the supervisor and paraprofessional must be known, respected, and understood. If they aren't shared, the nature of the relationship will not be open or one that grows. Those attitudes cover such arenas as:
 - Individual roles and duties
 - Persons with disabilities
 - Instructional styles
 - Management styles
 - Contributions of others (and each other)
- An understanding of similarities and differences between supervisor and paraprofessional must be recognized and understood. Those similarities and differences may relate to:
 - Values
 - Cultural and religious heritage
 - Levels of education
 - Levels of experience

- The health paraprofessional and the health nurse should develop and share a common vocabulary and a system of non-verbal cues. Verbal and non-verbal cues play an important part in communication. Gestures, facial expressions, posture, and eye contact are examples of non-verbal communication. Facial expressions give feedback about whether or not information has been understood, how it's being received, and the listener's attitude about the information. Posture and body movements also communicate attitude. Eye contact and facial expressions give a sense of positive (or negative) relationship between people.
- The supervisor must make sure directions and expectations are clearly understood and that the paraprofessional is able to perform the assigned tasks prior to implementing them.
- The paraprofessional must be willing and assertive enough to ask for clarification or assistance if the assignment is not understood. The paraprofessional needs to explain in an assertive (not aggressive) manner what he or she needs from the supervisor to be successful.
- The supervisor should discuss with the paraprofessional and then decide together what special interests, talents, and training the paraprofessional has that will complement and enhance and improve the delivery of services.
- The paraprofessional and his or her immediate supervisor must work to create a climate of cooperation, trust, respect, and loyalty by meeting regularly to discuss procedures and techniques that will establish and maintain open channels of communication.
- Silence is a form of communication. It's a difficult form of communication to understand because it can mean anger, or grief or depression. It can also mean that the listener understands what is being said. It's important to be assertive in your response when listening so the person who is trying to communicate with you knows your level of understanding and there is agreement. When you remain silent, you block that ability to have cooperative communication.

Communicating with Parents: The Paraprofessional's Role

Sometimes the paraprofessional knows the student better than almost anyone else because of the close relationship they have with individuals on a daily basis. This often creates a strong bond between the paraprofessional and students and their families. In many cases the paraprofessional is also the bus aide and rides to and from school or work with the individual. As a health paraprofessional, you may be directed to make calls home to parents about

health concerns. It may be natural for the parents to establish a relationship with the paraprofessional that is more consistent and regular than with other staff members. Information gathered or discussed in this setting must not be shared beyond the work setting. The paraprofessional must remember a few basic rules:

- Establish some ground rules with your supervisor, if you're in daily contact with parents, so you know clearly what communication is appropriate and what is not. Ask for clear boundaries.
- It may be efficient for you to deliver written contact to parents, but make sure the parents understand that you're only delivering information in behalf of the teacher or supervisor.
- Remember the rules of confidentiality at all times. Don't share information about other students or clients under any circumstances, unless otherwise advised.
- Remember that the teacher or supervisor is the person responsible for setting up instruction and planning for the individual. If the parent has concerns or questions, tell them you will give the information to the proper person, or ask them to make that contact. Never put yourself in a position where you are making decisions with parents that you don't have the authority to make.
- Make sure the student or client knows that you aren't to be placed in the middle of situations between home and school or organization.

The Loss and Grieving Process Related to Disability

Individuals who become disabled usually go through a grieving process involving five stages and is similar to that experienced when someone close has died. The stage a person is in can affect his or her attitude and ability to learn, work, and relate to others. The five stages in this grieving process are described as follows:

- **Denial:** The individual usually tries to ignore the disability and is not very emotional. This is the body's way of anesthetizing itself against the condition.
- **Anger:** The individual expresses rage at what has happened. Hostility is often directed at others. Self-pity often accompanies this stage.
- **Bargaining:** The individual tries to convince him- or herself and others if certain things are done the problem will disappear, and things will be like before (e.g., making promises, trying to "cut a deal"). This is usually the last attempt to ignore the condition before reality sinks in.
- **Depression:** Individuals may become introverted and secluded. At this stage self-pity becomes dominant in the individual. Suicide attempts are sometimes considered.

- **Acceptance:** The individual accepts the loss and its limitations. Plans are made to modify the life-style to achieve a new quality of life.

An individual should be allowed to progress through this process at his or her own rate. They may race through all five stages or skip some, or revert back or linger in one stage. They need help and understanding in order to reach the acceptance level.

- **Other variables** (from class discussion)
-
-
-

As a health paraprofessional, it's important for you to understand these stages because an individual may be referred to you or come to you regularly for medication. You may be one of the few people that sees them alone regularly and you may notice their emotional condition. You may want to talk to the individual based on the stage or process of grieving they may be in. You can be a tremendous support if you know these stages and offer support and understanding to the person. You also may be the person on staff who sees that psychological support may need to be requested for the individual.

All of these are important factors in your understanding the individual and his or her needs. The more you know about the individual's disability and how it has affected him or her, the more sensitive you will be to the need. Take time to ask the individual or read the records about the individual to be able to work most effectively with him or her.

Section 2

Problem-Solving Techniques

It's essential for paraprofessionals and other team members to work through differences in order to succeed in providing the best service to their clients or students.

When working side-by-side, day after day with your supervisor or supervising teacher, you're bound to have differences in the way you each feel situations should be handled. You may have differences revolving around procedure, personal issues, or techniques. The two of you may have different perceptions, learning styles, or clashing emotional needs. The conflict may often come from a source as basic as deciding how to use limited resources.

Conflict isn't necessarily negative. Conflict has some positive functions that are important to remember when working through differences. Some of those positives are:

- Questioning makes people have to clarify their positions.
- Questioning helps others look at different perceptions, concerns, and interests.
- Questioning encourages others to look for new facts.
- Questioning provides a source for developing more specific and long lasting solutions.
- Questioning gives the opportunity to establish mutual trust.
- Questioning results in personal and social change.
- Questioning prevents situation from getting worse.

The following are series of problem solving techniques developed by Anna Lou Pickett in *A Training Program for Paraprofessionals Working with Special Education and Related Services* (developed at the National Resource Center for Paraprofessionals in Special Education and Related Services at City University of New York in 1988). You may find these helpful in improving your ability to work better in a team and with your supervisor.

Step One: Identify and Describe the Problem

A situation must be seen and clearly understood before it can be resolved. It's not always easy to put a problem into words, but if it cannot be stated clearly, it will be impossible to choose a course of action that will lead to a satisfactory solution. Each person must describe the situation in his or her own words and from a personal point of view. This can be done by asking: "What's the problem?", "What's wrong?", "Who's involved?", "Who's affected?", "How are they affected?"

Step Two: Define and Determine the Cause of the Problem

It's essential, next, to determine what caused the problem. Was it caused by outside conditions (such as contractual agreements, budget crunches, etc.)? In this case the team may have little control over the situation, but can work together to decide how to "survive" it together or work to change it. The cause may be a misunderstanding of job roles and responsibilities. The problem may be caused by a difference in values, attitudes, age, work experience, education, cultural heritage, religious beliefs, or other personal traits. Whatever the cause, it must be clearly determined.

Step Three: Decide on a Goal and Identify Alternatives

Now you can develop strategies. Ask yourselves: "What do we want to achieve and how can we go about achieving it?" All those involved in the conflict should brainstorm a list of solutions. More information may be needed in some areas to have a workable list of solutions. Take the time to get all the information needed.

Step Four: Select and Implement a Course of Action

All those participating in the brainstorming should decide the solution that will fit the best for all involved. Everyone must agree on the solution, try it out and see if it works, and get back together to revise or change the plan as needed. Before making changes though, all should give the solution enough time to see if it will work since new behaviors and skills don't often change easily.

Step Five: Evaluate the Results

Revising and changing to meet the needs is essential. No solution is ever permanent. The group should regularly evaluate the solution and make adjustments as needed. If the solution isn't working, maybe help from outside sources is needed.

A Problem-Solving Work Session

Use the following steps from this work session adapted from *Building Team Pride* by Margaret Emery at the University of Missouri to help solve the problem and refocus you as a team.

- 1 Maybe the two of you aren't sure where the breakdown in communication took place. There's such tremendous diversity of experience and focus in the nature of your jobs. It's important to remember that you both have the right to be different and to be honored for your differences. Going through the exercise called "Breakdown Checklist" can help pinpoint the problem areas.

You can go through these questions together or individually. Just the act of doing the worksheet can be the spark that helps resolve the situation because as you answer the questions the problem area will become obvious. Then the two of you can talk through the problem and come to a solution.

- 2 If the problem continues or gets worse even after completing the Breakdown Worksheet, the Solution Worksheet will provide a collaborative structure for problem-solving. Notice that four steps exist in this model: *separate*, *focus*, *generate*, and *develop*. Each step requires that you create your response, record your partner's response, and develop a joint response. Therefore, you will need a copy of the worksheet for each of you. This may seem like a very elaborate process to go about problem-solving, but if you practice it as an exercise in class and with your supervisor, it will eventually become an automatic way of dealing with issues and it will become more natural to you to think of these steps in your head.

Teams are marked by mutual ownership. Using consensus during problem-solving discussions is critical to each of you so that you can claim ownership for the outcomes and solutions. Some important guidelines for using a consensus approach are:

- Listen and pay attention to each other.
- Ask open-ended questions using "what" and "how".
- Don't agree too quickly with each other.
- Generate multiple options (challenge the limits!).
- Treat options as alternatives not answers.
- Don't argue blindly for your views.
- Treat your differences as strengths.

The two of you will know you have reached a consensus when:

- Both of you agree on a single alternative.
- Each of you can honestly say:
"I believe you understand my point of view."
"I believe I understand your point of view."
"Whether or not I prefer this decision, I support it because it was arrived at fairly and openly and it's the best solution for us at this time."

Twelve Barriers to Communication

Judgement

- **Criticizing:** A judgemental roadblock is criticism. Parents think they need to judge their children or they'll never become hard-working, mannerly adults. Teachers and professionals think they must criticize students in order for them to learn.
- **Name Calling:** "Putting down" or stereotyping the other person: "What a dope!", "Just like a woman!", "Egghead", "You're just another insensitive male."
- **Diagnosing:** Analyzing why people are acting the way they do; playing amateur psychologist. "I can read you like a book." "You're doing that just to irritate me." "You think you're better than I am just because you went to college."
- **Praising Evaluatively:** Making a positive judgement of the other person, or his or her actions or attitudes. "You're always such a good child. I know you'll help me with the lawn tonight."

Sending Solutions

- **Ordering:** Commanding the other person to do what you want to have done. "Do your homework right now." "Why? Because I said so!"
- **Threatening:** Trying to control the other's actions by warning of negative consequences you will instigate. "You'll do it or else..." "Stop that noise right now or I'll keep the whole class after school."
- **Moralizing:** Telling another person what he or she should do.

"You shouldn't get a divorce – think of what will happen to the children.", "You ought to tell him you're sorry."

- **Excessive or Inappropriate Questions:** Closed-ended questions are often barriers in a relationship; these can usually be answered in a few words, often with a simple "yes" or "no". "When did it happen?", "Are you sorry you did it?"

Avoiding the Other's Concerns

- **Advising:** Giving the other person a solution to his or her problems. "If I were you, I'd..."
- **Diverting:** Pushing the other's problems aside through distraction. "Just try to think about something more pleasant.", "Think you've got it bad? Look at what happened to me."
- **Logical Argument:** Attempting to convince the other person with an appeal to facts or logic, usually without consideration of the emotional factors involved. "Look – if you hadn't bought that new car, we'd be able to make the down payment on a house."
- **Reassuring:** Trying to stop the other person from feeling the negative emotions she or he is experiencing. "Don't worry: it's always darkest right before the dawn.", "It'll all work out in the long run."

Adapted with permission from training materials developed by the Minnesota Federation of Teachers and the American Federation of Teachers.

Problem-Solving Role Play Situation

Role play the situation below with a partner and then consider the questions that follow this scenario.

Scenario: Without the opportunity to talk it through with the school nurse, you made the decision that a student with asthma (which you treated daily) could make the trip on the city bus (unaccompanied) to his job site. Part of that decision came about because you were short-handed, many other paraprofessionals and staff members were out sick, and school nurse and student's parents were unavailable to help make this quick decision. The student reassured you he had his medication needs under control and could take care of them independently. The student made the trip okay, but had expressed some concerns to friends in the hall on his return. The principal overheard these comments and understood the concerns to be much more serious than they were. You, therefore, were held responsible for letting the student go to work unattended. The principal talked to you and the supervising nurse about your "poor decision-making skills".

- What are the issues to resolve in this situation?

- Did the paraprofessional make the right choice of how to handle this situation "in a pinch"?

- After the situation has occurred, how do you think the paraprofessional should talk to the student about what happened?

- To the principal?

- To the supervising nurse?

Breakdown Checklist

Directions: Respond to each question by checking "yes" or a "no". Your responses can be made together or individually. If you choose to work individually, have the teacher use the appropriate checklist column, fold it under, and then have the paraprofessional check the appropriate column. Once you are done with this, discuss the similarities and the differences between answers.

	Para		Teacher	
	Y	N	Y	N
1 Am I sharing information about student performance & growth?	☐	☐	☐	☐
2 Are we conferencing frequently enough?	☐	☐	☐	☐
3 Do we set aside time to applaud each other's successes?	☐	☐	☐	☐
4 Do I recognize my partner's freedom to reject as well as to accept solutions?	☐	☐	☐	☐
5 Do we need to work specifically on any of these areas?				
• <i>Territoriality</i>	☐	☐	☐	☐
• <i>Joint responsibility</i>	☐	☐	☐	☐
• <i>Job descriptions</i>	☐	☐	☐	☐
• <i>Goal setting</i>	☐	☐	☐	☐
• <i>Student evaluations</i>	☐	☐	☐	☐
• <i>Role clarification</i>	☐	☐	☐	☐
6 Are we setting expectations that are too high?	☐	☐	☐	☐
7 Are we setting them too low?	☐	☐	☐	☐
8 Do I focus on present & future issues and not past difficulties?	☐	☐	☐	☐
9 Do I describe to my partner rather than judge?	☐	☐	☐	☐
10 Do I focus on specifics rather than generalities when I talk?	☐	☐	☐	☐

Adapted with permission from *Building Team Pride* by Margaret Emery from the University of Missouri.

Solutions Worksheet: *Differences Lead to Solutions*

1 • Separate People from the Problem

Differences in issue disputes are generally defined by differences in perception between you and your partner.

Goal: *To reduce areas of conflict in perception.*

- Your Response: *I think the problem is...*

- Partner's Response: *My partner thinks the problem is...*

- Joint Response: *Together, we think the problem is...*

2 • Focus on Interests Rather than Positions

For every interest usually exist several possible options that could satisfy it while every personal position generally supports only one interest. Therefore, in order to develop mutual solutions to support several positions, the two of you should focus on clarifying interests.

Goal: *To identify interests behind positions.*

- Your Responses:

The people involved in this problem are...

The problem exists because...

A behavior I display that contributes to the problem is...

A behavior _____ displays that contributes to the problem is...

• Partner's Responses:

The people involved in this problem are...

The problem exists because...

A behavior I display that contributes to the problem is...

A behavior _____ displays that contributes to the problem is...

• Joint Responses:

The people involved in this problem are...

The problem exists because...

A behavior I display that contributes to the problem is...

A behavior _____ displays that contributes to the problem is...

3 • Generate a Variety of Solutions

The two of you aren't trying to search for a single answer, but are trying to broaden options available by generating multiple alternatives.

Goal: *To invent creative options.*

- Your Options: *Three alternatives for dealing with the problem are...*

- Partner's Options: *Three alternatives my partner sees for dealing with the problem are...*

- Joint Options: *Three alternatives we see for dealing with the problem are...*

4 • Develop Situations Based on Criteria

The more the two of you apply standards of fairness, efficiency, and resource availability to bear on problems, the more likely you will be to produce a solution based on consensus.

Goal: *To choose and implement an option based on objective criteria.*

- Your Response: *I would choose option _____ because...*

- Partner's Response: *I would choose option _____ because...*

-
-
-
- Joint Response: We would choose option _____ because...
-
-
-

As the teacher, I will...

As the paraprofessional, I will...

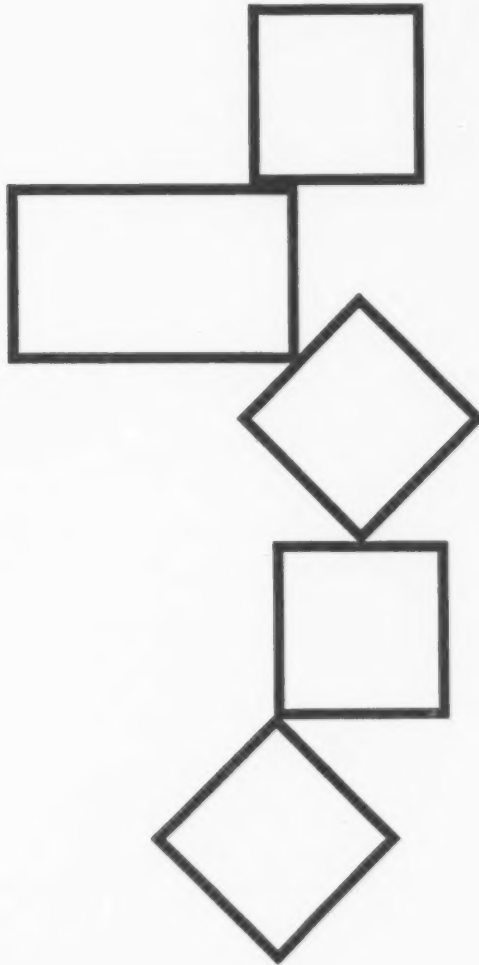
We have the following materials:

We can consult the following resources:

We can ask _____ to assist by...

We can implement this option by _____, and evaluate its effectiveness by observing the following:

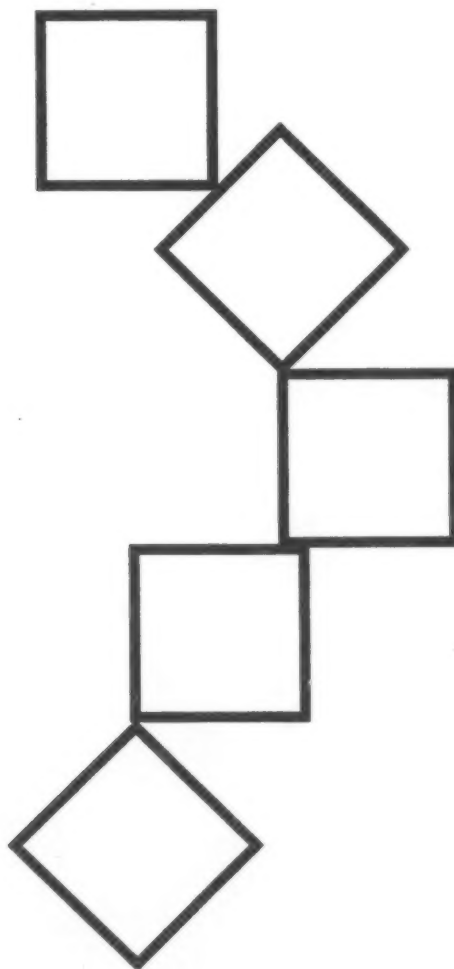
One-Way Communication



Instructions

- 1 Describe this diagram to the people in the audience.
- 2 Tell them they should draw the diagram following your instructions.
- 3 You may tell them only once and you may not use gestures.
- 4 Tell them the following rules:
 - They can't ask questions
 - They can't talk to one another
 - They can't look at one another's papers.
- 5 Once they've completed this task, have them move on to "Two-Way Communication".

Two-Way Communication



Instructions

- 1 Describe this diagram to the people in the audience.
- 2 Tell them they are to draw the diagram given your instructions.
- 3 You may repeat your directions as often as needed.
- 4 Tell them they may ask questions, get clarification, and use gestures.

"One-Way Communication" and "Two-Way Communication" have been adapted from *A Handbook of Structured Experiences for Human Relations Training, Vol. I, revised*, J.W. Pfeiffer & J.E. Jones, editors, La Jolla, CA: University Associates, Inc., 1974.

Summary

Communication is vital in work relationships, as well as other relationships in life, and it's essential in working with peers, supervisors, students, and students' families. We communicate most obviously by what we say and write, but also through our actions, expressions, and other nonverbal cues. Without quality communication efforts, students would not learn, grow, and develop as they should be able to do.

Questions to Ponder

- Reflect back on a past experience when communication had a positive influence in your life and also on a negative experience when communication was lacking. What have you learned from these experiences?
- How can you use written communication more effectively?
- How does using nonverbal communication influence your message? Give three examples.

7

Chapter Seven

Teamwork

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Teams
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Know to be Effective Team Members
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Introduction

The skills and attitudes a new employee needs on any job vary greatly, but what is important on any job is the ability to work in teams. This is extremely important for paraprofessionals because a paraprofessional will typically be called on to collaborate with many professionals in working with the same student or client. The more effective the team can work together, the better the programming for and with the individual and his or her family.

What is the purpose of a team? For our purposes, a team works together to develop a plan that best meets the needs of those individuals with disabilities with whom it works. The team may work to develop initial planning with an individual and his or her family and/or work together to problem solve situations as they arise.

These goals are important to have an effective team:

- An understanding of each person's role on the team.
- An understanding of the purpose of the team.
- An ability to talk to each other about issues that affect the efficiency of the team.
- A willingness to support each other in the team.
- An understanding of how the team works.
- An ability to effectively work through both interpersonal and task-oriented problems that happen within a team.
- An ability to use conflict in a positive way.
- An understanding that more team collaboration means less competition to provide the best services for the individual.
- An ability to work with other groups to assist the individual.
- A sense of interdependence among team members.

Section 1

An Example of Teamwork: Individualized Planning

A perfect example of teamwork is the development of an individual plan. There are many types of individual plans developed for individuals with disabilities. Some of those are listed below.

Individualized Health Plans

The individualized health plan (IHP) is a written plan used to respond to the needs to the health needs of the student with chronic illnesses or physical disabilities. This plan provides a for-

mat for summarizing health information, a problem statement, and goals and objectives. Some of the information may relate to the student's academic needs also if the health condition affects the learning process. (See the example of an IHP in Appendix J.)

Individualized Educational Plan

The Individualized Educational Plan (IEP) is a written plan authorized and developed under PL 94-142 (now PL 101-476, or IDEA). The IEP is a written plan for any student with a disability who qualifies for and receives services in the public school system. Four important requirements of IDEA concern notification, participation in meetings, content of the IEP, and agency responsibility. The IEP describes the student's needs, outlines the instructional program, and defines services needed to meet the student's needs. In order to develop this plan, a multidisciplinary team meets to determine the needs of the student. This team should include the student, parents, school psychologist, the regular teacher, special education teacher, paraprofessional, nurse, any community agency representatives involved with the student, and anyone else involved in planning for the unique needs of students.

The team meets to determine the student's:

- Strengths and weaknesses.
- Learning potential.
- Needs for learning.
- Accommodation or modification needs.
- Learning style.
- Extent he or she will participate in regular education.
- Related service needs.

A plan based on these discussions is written which the student and parents agree to and sign.

Individualized Family Service Plan

The Individualized Family Service Plan (IFSP) is developed for young children with disabilities and their families. The impetus for the development of this plan came out of federal legislation that extended educational provisions under the age of five (PL 99-457). The purpose of the IFSP is to identify and facilitate the use of formal and informal resources that reflect the families' priorities for their children and themselves. The IFSP must include:

- Information on the child's present level of functioning.
- The strengths and needs of the child's family.
- Major goals for the child and family with criteria, procedures and time-line.
- Specific services necessary to meet the needs of the child and family.

- Dates for initiation and duration of services.
- Assignment of a case manager most immediately relevant to the child's needs.
- Steps to support the transition to preschool services

Individual Service Plan

The Individual Service Plan (ISP) is a plan for persons with mental retardation or related conditions who apply for services. The ISP is developed by the case manager with the person with mental retardation or related condition, the person's legal representative, and the person's advocate, if any. The ISP must include:

- Results of the diagnosis.
- Summary of assessment information and recommendations.
- A written summary of needs identified in the diagnosis and assessment.
- Identification of all service needs, including the type, amount and frequency of the services needed, including services to be provided by the case manager.
- Actions that will be taken to develop or obtain the services identified, including those services not currently available.
- Long-range goals and an anticipated date for attainment of goals.
- Annual goals related to attaining the long-range goals.
- Information that providers must submit to the case manager and the frequency with which the information must be provided.
- The signatures of the person and legal representative to document that the ISP has been reviewed and that the person agrees to the goals and service specified.

Individual Community Support Plan

Yet another type of individual plan is called the Individual Community Support Plan (ICSP). This plan is written by a case manager and the person with a serious and persistent mental illness. The ICSP must include:

- Goals for the person.
- Services needed by the individual.
- Goals for each service.
- Amount, scope, frequency, and duration of each service.
- Frequency of face-to-face contact between the person and case manager needed to implement the ICSP.
- Services involving the individual's family or primary caregiver or other interested persons.
- Steps the people and case manager will take to assure the individual's access to services identified in the plan.

Individualized Written Rehabilitation Program

The last individual plan to be cited here as an example of individual plans for persons with disabilities is the Individualized Written Rehabilitation Program (IWRP). Once a person is eligible for vocational rehabilitation services, the counselor assists the individual in identifying vocational goals. Those goals are developed in the IWRP. The vocational rehabilitation counselor will work on this plan with the individual and the case manager and any other agency people. The objectives and services in the plan are designed to overcome the barriers which were identified in the diagnostic study as those keeping the person from employment.

Case Management and the Individual Plan

Each individual plan has a case manager. If the case manager isn't the LSN, the SHP could receive direction from both the case manager and the LSN. Should their directions conflict, the SHP will discuss his or her concerns with the LSN.

The Paraprofessional's Role in the Individual Plan

In each of these individual plans, it's essential that paraprofessionals be involved in the process because they often work most directly with individuals with disabilities. The health paraprofessional should at least be consulted about input in the student planning session. It may be that he or she has little input on many students who don't require special health care, but if the student is a regular in the health office or has any medically fragile conditions, it's imperative that the school nurse and the health paraprofessional be involved in the planning process.

If the paraprofessional is also the bus aide, he or she may also be the one staff member who has regular contact with the parents. Therefore the paraprofessional often knows an individual *and* family's needs intimately. However, in reality the paraprofessional is never involved in the individual plan meetings, which are either scheduled when he or she is not on site (i.e., bus duty), or the paraprofessional is not asked to attend.

It's very important as part of your team development skills that you emphasize the importance of your attendance at these meetings as a paraprofessional. You're a crucial link. At the very least, you need to be given the opportunity to write a report of your work with the students and recommendations. Because paraprofessionals are being given more responsibility, it's essential they also be involved in the planning of the individual plan and given credit as the vital team member.

Results of Workable Teams

- Goals are realistic and possible because everyone contributes in developing them.
- Team is committed and supports each other.
- Priorities are understood and agreed upon.
- Ideas and communication are encouraged.
- Problem solving is done effectively.
- Feedback is honest and "on target".
- Conflict is okay, and is even seen as a normal way to discuss and solve problems.
- Team members get support from each other to be productive team members and productive in their personal goals.
- Team members encourage each other to try new ideas with clients/students and they support each other for those efforts.
- Team members understand the importance of each member in the team and as an individual.

Section 2

Team Members

Role definition is essential to any successful team effort. With an integrated team made up of professionals, paraprofessionals, therapists, nurses, parents, and consumers, it's important to make everyone's role clear. Whether you will be working in a direct service setting or an educational setting, your role on the team needs to be made clear to you. That's the responsibility of your supervising nurse.

As a guideline to typical roles that team members can have, the following is an overview of team roles adapted from a presentation at the 1987 Arc-Minnesota Conference by Linda Kjerland, Judy Neiss, Barb Franke, Chris Verdon, and Ellen Westman.

Roles

Individual with the disability

- Presents personal values and priorities.
- Advocates for personal accommodations or modifications.
- Provides insight into personal goals and future planning.

Parents

- Present family values and priorities for the individual's level of functioning.
-

- Provide insight into the individual's functioning in various environments.
- Provide a vision of the individual's future.

Regular Education Teachers

- See and include the individual as a member of the class, not a visitor.
- Seek and use others to adapt learning activities to include the individual in meaningful ways.
- Incorporate IEP goals in typical activities and interactions.

Special Education Teachers

- Provide consultation and collaboration.
- Adapt curriculum, materials, and equipment.
- Incorporate IEP goals in typical activities and interactions.

Licensed School Nurse

- Provides health information, daily condition and needs.
- Provides health history, causes, prognosis, etc.
- Provides description and help arrange for special health accommodations needed.
- Provides information for IHP to the team.
- Provide consultation on how to accommodate the individual in the working/classroom setting.

Paraprofessionals

- Facilitate the individual's participation with peers or adults.
- Incorporate IEP goals in typical activities or interactions.
- Assist and perform personal care skills when necessary.

Therapists

- Ensure functional approaches to addressing therapy needs in typical activities and interactions such as self care, getting on the bus, and finding the bathroom.
- Adapt the curriculum, materials, and equipment.
- Incorporate IEP goals in typical activities and interactions.

Administrators

- Draw together regular and special education resources.
- Ensure staff training and team consultative support.
- Assist in problem solving logistics and program issues.

Case Manager

- Bring together the individual with a disability and necessary services and supports.

- Identify the need for planning, seeking out, acquiring, authorizing, and coordinating services.
- Monitor and evaluate the delivery of services.
- Evaluate the delivery of services.
- Protect the rights of the individual.

Section 3

Essential Elements of Effective Teams

Many essential elements make up effective teams and each one works differently in a given team. It's important to understand these elements in your work as a paraprofessional on a team.

Positive Interdependence

This means that each group member sees him- or herself as linked with each other member in a way that one member cannot succeed unless other members succeed. It also means that the work of each member of the team helps you in your efforts and your work helps them in their efforts with the individuals with whom you both work.

Individual Accountability

This means that you and every other member in the team has a responsibility to the group to follow through on assigned tasks with individuals. The team depends on you to follow through. It also means that every member of the team has the responsibility to give extra assistance to each other and offer encouragement to each other when asked for or needed. When everyone on the team is individually accountable in these ways, it's a "safe" environment for everyone and the goal of working for the client's or student's best interests is clear.

Face-to-Face Interaction

This means the amount of actual participation you have in the team. The smaller the team, the more chance you have to be actively involved. The larger the team, the less direct interaction and involvement you have a chance to be involved in. Smaller teams are better. The smaller the team, the more you will feel directly linked to the other members and the easier it will be for you to work directly on the needs of clients or students.

Collaborative Skills

This means cooperation, sharing, and working together for a

common cause. It doesn't mean personal issues or personalities take importance over the "product" of service delivery. It doesn't mean that people are put together on a team because of their role or position and then not given equal opportunity to contribute. Each team member must feel they have something to share and contribute in providing for the well being of the student or client and they must be allowed to share that information.

Group Processing

This means the team needs to set aside time to talk with each other about how well they are doing working together on their goals for clients or students and their working relationship with each other as team members.

The team needs to develop a good balance between outcome goals (those for the client or student) and process goals (developing an effective team). If the team has some real difficulties with roles (whose job is this?) or positive supportive behaviors toward each other, they may need to call someone from the outside in to help set up some stable boundaries.

Adapted with permission from training materials developed by the Minnesota Federation of Teachers and the American Federation of Teachers.

Section 4

How Teams Really Work

A team has three functions: task functions, maintenance functions, and anti-group functions. These three functions are described below.

Task Functions

These functions focus on intelligent problem-solving aspects. These are the actual goals – the reason the team is formed. In the case of a student IEP for example, the team is called together to determine the objectives for the year. Those goals are determined by the group in the following ways:

- **Initiating:** Discussing what could be done or how the challenges of the client or student could be approached. This is when ideas are collected, suggestions are made, procedures are reviewed for possible solutions.
 - **Regulating:** Regulating the direction by summarizing what has been done in the past, stating time limitations, restating the goals.
 - **Information Seeking:** Asking for additional clarification on suggestions.
-

- **Information Giving:** Offering facts or generalizations which relate to personal experiences pertinent to the particular situation being discussed.
- **Opinion Giving:** Stating beliefs or opinions about the decision the group should make.
- **Elaborating:** Giving examples or developing further understanding by offering rationale for suggestions made.
- **Coordinating:** Clarifying all the suggestions made for the student or client and trying to decide which suggestions are the most appropriate.
- **Orienting:** Summarizing what has happened, pointing out problems and raising questions about whether more information from outside is needed or if decisions can be made.
- **Evaluating:** Helping the group to evaluate decisions, goals, procedures, and checking to see if the group is in agreement or deciding what further steps need to be taken before a consensus can be reached.

Adapted with permission from training materials developed by the Minnesota Federation of Teachers and the American Federation of Teachers.

Maintenance Functions

These functions focus on the personal relations among members in the group. These functions help a group maintain itself so the focus of the team can be the tasks, the service to clients or students and their families, and not interpersonal conflicts within the group. These ideas can be used by the team leader or any member of the team to work toward building the relationships on the team. This sort of supportive action leads to groups who work much more collaboratively.

- **Supporting:** Creating an emotional climate which holds the group together and makes it easier for each member to want to contribute. One way this is done is in agreeing with the suggestions of others and offering positive feedback when someone makes a suggestion, or adding on to a suggestion with your own additional thoughts.
- **Harmonizing:** Mediating differences between team members or relieving tension with a joke/story about a similar situation.
- **Gate-keeping:** Noticing certain team members who have not spoken and asking them their opinion or asking them to relate something that fits into the conversation. This helps members who may be feeling isolated to come back into the conversation.
- **Encouraging:** Praising and accepting others' ideas. This creates a warmth and a friendly feeling of belonging and helps others become more responsive.

- **Compromising:** Admitting when you're wrong, or modifying your ideas when you hear other input that makes you realize collaborating ideas creates a stronger decision or choice.

Adapted with permission from training materials developed by the Minnesota Federation of Teachers and the American Federation of Teachers.

Anti-group Functions

These functions focus on members' individual needs and behaviors that can be barriers to completing the group tasks. They don't help the team work as a unit. In these functions, the group goals are forgotten and the individual acts primarily to satisfy personal needs. These are behaviors which, although unavoidable at times, a group works to prevent:

- **Blocking:** Being negative, and unreasonably resistant, trying to bring back issues the group has already rejected.
- **Self-confessing:** Using the group to express personal problems and gain sympathy.
- **Recognition-seeking:** Calling attention to oneself and describing personal achievements and boasting.
- **Dominating:** Attempting to take over by interrupting others, flattery, or asserting superior status, asserting authority or manipulating the group or individuals in the group.
- **Cynical:** bringing up unrelated subjects, being cynical about what team meetings like this accomplish, or displaying a lack of involvement.
- **Special interest pleading:** Stereotyping what is best for others or the group when one is really hiding one's own biases or prejudices in the stereotype used.
- **Aggressing:** Questioning the competence of the people giving their opinions, joking aggressively, showing envy by trying to take credit for others' ideas, expressing disapproval of values, acting on feelings of others.

Adapted with permission from training materials developed by the Minnesota Federation of Teachers and the American Federation of Teachers.

Section 5

What Paraprofessionals Need to Know to be Effective Team Members

In order to be an effective paraprofessional, each person should know and understand these elements of their job.

Job Role

You need to know what your role is and how that role functions within the team. At this point in this training you have done exercises to help you better learn what your role is or should be in a given setting.

Responsibilities

You need to know as much as possible about your responsibilities. In learning what your role is and what a paraprofessional job description is (or should be) in your setting or the setting you chose to explore, you should have a general sense at this point in this training of what the job responsibilities are for a paraprofessional in a general sense.

Goals

Each team's goals are established by its members. First of all, as a paraprofessional, you need to know you're on the team. You deserve to be treated like a team member. You also need to have a clear sense of the goals of the team. Those goals may be set up for one individual. The goals may be basic philosophical goals of the organization or school. You may be on several teams with several different sets of goals. It may seem, at times, like a juggling act to keep the goals separate for each team you participate on, but it's extremely important that you keep the goals separate and clear.

Time

You need the time to participate on teams and to work closely with staff. This is a goal that must constantly be stressed as essential in paraprofessional job roles and responsibilities. To be an effective team, meetings and planning times must be scheduled when members can attend and members must also be given the time to prepare for conferences and staffings. This is all part of being viewed as a valued member.

Communication

You need to know how to communicate well with others. In order to get your views across to others and make your points clear,

you need to have good, clear communication skills, as presented in the next section of this training.

Activity: How Can You Resolve This Teamwork Dilemma?

Read the following situation, then break up into small groups and discuss how you would handle this situation as a group. Share your ideas with the larger group when you get back together again.

Tim is a paraprofessional in a classroom where there are three other paraprofessionals, four teachers, and twenty-two high school students with multiple disabilities. It seems to the other three paraprofessionals that Tim is out of the room and unavailable every time John needs to be toileted. John is a large student who is difficult to toilet and the staff takes turns. Tim is never available at the right times. When asked about this, Tim says he isn't trying to be unavailable. He always seems to have a legitimate excuse. When the three paraprofessionals went to the lead teacher with this concern, she said the paraprofessionals needed to come up with a system among themselves to work this out.

Assume you're on this team of four. What will you do? Work this through, in discussion, with your group.

Summary

Each individual member of a team contributes to the goal of the team. Alone they will make an impact on the student or family; however, with the whole team working together for the common goal a larger, efficient, more uniform, and consistent impact will be made. Team members who understand each others' roles in the team help the team work cohesively. Other issues to consider are respect of team members, common goals of the team, spirit of collaboration, and team philosophy of interdependence.

Questions to Ponder

- Share an example of team cohesiveness. How did this make the team goals more attainable?
- As a paraprofessional, how do you see your role as a team member?
- Name four ways you can be an effective team member.
- What are three emergency care issues the SHP needs to be aware of?

8

Chapter Eight

Caring for Individuals with Disabilities

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Introduction

This chapter is designed to give the health paraprofessional general background information about the most common types of conditions they may address in the school health office. These conditions represent those which are considered medically fragile or that commonly affect individuals with disabilities. This list was determined by the Minnesota School Health Paraprofessional Advisory Committee in July, 1993.

This chapter presents each condition alphabetically in its own section. Many of these descriptions are taken from fact sheets and publications from local, state, or national organizations that deal with one specific disorder or disease. Each description ends with a summary section called "Why This Information is Important for the Health Paraprofessional".

Our intent is for you to read each section and formulate questions and concerns which you can share in class with your instructor and other class members.

Section 1 *Allergy*

Allergy is an exaggerated response to substances which usually cause no difficulty in most individuals. Our immune system normally protects us from a variety of outside infectious agents, particularly viruses and bacteria. On the other hand, the immune system in some of us actually causes allergic diseases.

Allergy, among the most common diseases experienced by Americans, is believed to affect the lives of as many as forty million children and adults. Taken for granted or often confused with colds or other illnesses, people with allergies can easily dismiss or ignore their causes and, consequently, the various methods that are available to control these very real, disturbing, and often costly diseases.

The most common allergic diseases are:

- **Allergic rhinitis** (or hay fever), appearing clinically as nasal stuffiness, sneezing, nasal itching, clear nasal discharge, and itching of the roof of the mouth and/or ears.
- **Allergic asthma**, with symptoms of wheezing, coughing, and shortness of breath.
- **Allergic conjunctivitis** (or eye allergy), producing redness and itching and chronic mucus-related discharge.
- **Allergic eczema**, an allergic skin rash.
- **Allergic contact dermatitis**, (i.e., poison ivy).

Causes of Allergy

Allergens

The substances that cause allergic disease in susceptible people are known as *allergens*. They enter our bodies in a variety of ways: by inhalation (pollens, dust, mold spores, and cat and dog dander); by ingestion (shrimp, peanuts); by injection (penicillin, insect bites); or by absorption through the skin (poison ivy).

Most allergies of the nose, eyes, and lungs are caused by plant pollens carried by the wind. These pollens are produced at various times of the year when plants discharge literally billions of pollen particles into the air which can be carried significant distances. Unlike the wind-pollinated plants, conspicuous wild flowers or flowers used in most residential gardens are pollinated by insects and are therefore not widely capable of producing allergic disease.

Heredity and Allergy

The capacity to become allergic is an inherited characteristic. Although you may be born with the capability to become allergic, you're not automatically allergic to specific allergens. Several factors must be present for allergic sensitivity to be developed:

- The specific genes acquired from parents.
- The exposure to one or more allergens to which you have a genetically-programmed response.
- The degree and length of exposure.

A baby born with the tendency to become allergic to cow's milk, for example, may show allergic symptoms several months after birth. A genetic capability to become allergic to cat dander may take three to four years of cat exposure before the person shows symptoms.

On the other hand, poison ivy allergy (contact dermatitis) is an allergy in which heredity doesn't play a part. The person with poison ivy allergy first has to be exposed to the oil from the plant. The first exposure may sensitize or cause the person to become allergic and, when subsequent exposure takes place, a contact dermatitis rash appears and can be quite severe. Substances other than plants, such as dyes, metals, and chemicals in deodorants and cosmetics, can also cause a similar dermatitis.

Many people wonder whether or not they will outgrow their allergies. Although allergic asthma and other allergic diseases may spontaneously improve, particularly during childhood and adolescence, it may also worsen or reoccur any time during life. It's no longer thought that people outgrow these diseases. The diseases sometimes do become dormant and free of symptoms. Still, allergic disease can return or even have its initial onset later in life.

Correctly Diagnosing Allergies

A number of diseases can appear to be allergic but upon professional examination prove not to be so. For example, you may have nasal symptoms that are due to chronic and repeated infections and have symptoms similar to allergic rhinitis. Some people with asthma lack allergies to any substance. It's important therefore to show proof of allergy whenever it's suspected because the treatments for allergic and non-allergic disease can be quite different.

Treatment Choices

Self-Improvement

Some people with allergic disease caused by airborne allergens improve by themselves. This can happen for several reasons, such as relocation to an area where the allergens are not found or decreased sensitivity or increased tolerance to allergens due to activation of normal protective immunologic mechanisms.

Interventions

There are several approaches for controlling allergy by reducing or eliminating symptoms:

- Avoid the offending allergen: remain within a well air-conditioned building; learn to recognize and avoid poison ivy and certain foods.
- Take medications: numerous medications, either prescribed or over-the-counter, are available and offer relief for many people.
- Get immunized against allergens to which you are allergic. This form of therapy is usually reserved for more severe cases or for persons in whom other forms of treatment have not been successful.

People with allergies are often susceptible to other substances in the environment. Although substances such as soap powders, cigarette smoke, perfumes, and odors from certain plants surely irritate the respiratory tract of some people, the symptoms they experience are not the direct result of an allergic mechanism. In no way does this minimize the importance of reducing or avoiding these irritants.

Adapted from R.F. Lockey, M.D., et. al. *Asthma and Allergy*. Asthma and Allergy Foundation of America: Washington DC.

Why This Information is Important for the Health Paraprofessional

You may have many occasions to see individuals who have allergies. They may have regular medications you will store and administer. They may have conditions where they react to only certain environments and situations (like bee stings or seasonal allergies). It's important for you to keep a record of individuals who have particular allergies to certain foods, insects, or conditions. It will be your responsibility to alert the school nurse that he or she, the student, and the parents develop an Emergency Care Plan were severe reactions to allergies can be anticipated.

Sometimes these allergic reactions can be so severe that you need to be able to react immediately. Make sure you familiarize yourself with the individuals who have severe allergy reactions. Most individuals you come in contact with will have allergy conditions where you will need to administer medications prescribed by a physician or over-the-counter medications brought from home.

Section 2

Asthma

Asthma is a common respiratory disease that affects an estimated five percent of the American population. Yet, much remains to be learned about asthma, including its cause and prevention. Current medical knowledge and self-education can allow most people with asthma to manage this disease and lead productive, relatively unrestricted lives.

Among the various definitions of asthma, all focus on these principal features: increased responsiveness of the trachea (windpipe) and bronchi (main airway) to various stimuli, appearing as a widespread narrowing of the airways that changes in severity either spontaneously or as a result of treatment.

A number of terms are part of the definition of asthma and key features of this disease. They include the *airways*; *hyperresponsiveness* or *hyperreactiveness*; *obstruction*; and *reversibility*.

It's important that you understand the meaning and significance of these terms, in order to appreciate symptoms, altered lung function, diagnosis, and – most importantly – treatment.

Major Features of Asthma

The Airways

Airways are passageways that carry air into the lungs for the eventual distribution of oxygen to the blood. Airways begin with the trachea (windpipe), which divides into increasingly smaller

tubes as it goes deeper into the lungs. The airways are composed of a number of important parts – mucous membranes, smooth muscle, blood vessels, and nerves – all of which contribute to respiratory symptoms in asthma and the subsequent disease process.

Hyperresponsiveness or Hyperreactiveness

This is the underlying abnormality in asthma, and what separates asthma patients from other individuals. Precisely why or how the bronchial airways in asthma are abnormal is not known. However, as a consequence of this abnormality, the airways in the asthma patient tend to constrict more quickly and easily than in the non-asthmatic person. The hyperreactivity of the asthmatic airways can change and become more sensitive or less reactive when treated. The increase in airway responsiveness sets the stage for patients to have “attacks” of asthma.

Obstruction

The airways narrow during an asthma attack. This is called *airway obstruction*. Obstruction is caused by a number of factors that reduce – or, in extreme conditions, block – air movement as it enters and exits the lungs. Four major elements in airway obstruction are contraction of the bronchial smooth muscle (bronchospasm); mucus formation; inflammation; and edema (swollen lung tissue).

The degree to which these factors contribute to airways obstruction determines the severity of the asthma attack.

Reversibility

The obstructions in the airways during an attack of asthma aren't permanent but may return to normal either spontaneously or, more commonly, as the result of treatment. The bronchial airways typically return to normal soon after treatment, while swelling in the airways takes weeks to disappear. The changes in bronchial tube function aren't permanent nor will they necessarily injure the lung.

Symptoms of Asthma

The usual symptoms of asthma are cough, shortness of breath, and wheezing. In addition, individuals with asthma experience chest tightness, which again can be intermittent, following exposure to a trigger, or continual. The individual can often not tolerate exercise, may experience chronic fatigue from extra effort in breathing, or may even experience weight loss when illness is severe.

These symptoms aren't necessarily confined to asthma. They can be found in association with other lung diseases, such as bronchitis or emphysema. In these and other forms of lung disease, the symptoms are usually present all the time and respond poorly to treatment. There's no one specific symptom or finding that can

be said to conclusively prove the existence of asthma.

Patients with asthma may experience symptoms only occasionally, frequently, or continually. The severity of an individual's asthma can vary greatly, from being a mild nuisance to life-threatening. In addition, symptoms of asthma may be severe in one individual's case while it may not interfere with normal living in another's.

Triggers of Asthma

Symptoms are usually triggered. It's common for a patient to experience symptoms of asthma with exercise, around irritants (including tobacco smoke), with a cold, or during an allergic reaction to allergens such as pollen, dust, animal dander, or certain foods. Symptoms are usually worse at night. Furthermore, it's common for symptoms to become severe enough at night to awaken the patient or even cause the need for prompt emergency care.

Forms of Asthma: Acute vs. Chronic

Acute asthma is usually called an *attack*. The bronchial tubes suddenly narrow and the patient is acutely short of breath and wheezes. Acute asthma can be triggered by allergies, may follow exercise, or occurs during a cold or without any apparent reason. Its suddenness and severity is frightening and creates a medical emergency that requires prompt treatment.

Chronic asthma produces symptoms on a continual basis. In chronic asthma, symptoms, while present, are more difficult to detect because our appreciation of asthma as a chronic, ongoing, persistent illness is a relatively new concept.

Airway Inflammation and Asthma

The major reason for chronic asthma is the existence of ongoing airway inflammation. By inflammation, we are referring to factors that cause airway injury.

Inflammation is more likely to occur and become severe the longer asthma goes untreated. While the signals for the body to produce airway inflammation in asthma aren't fully understood, we do know that there are signals that originate in the lungs, directing circulating white blood cells into the bronchial tubes. Cells already present in the lung also participate in the inflammatory process and cause further tissue injury. When cells either already in the lung or attracted to the lung are activated, they release a variety of chemicals that cause swelling, destruction of airway tissue, and changes from normal lung function. In addition, airway inflammation makes the bronchial tubes more reactive. This means it will take less of a trigger to cause more asthma.

All patients with severe, acute asthma have airway inflammation. Patients with chronic asthma, moreover, have airway inflammation present all the time. It's the development of airway inflammation that leads to chronic asthma.

Allergies and Asthma

Allergies are important in asthma. In allergic people, exposure to allergens stimulates the production of Immunoglobulin E (IgE), the allergy antibody, which signals certain cells to produce and discharge chemical agents that can trigger asthma by contracting bronchial smooth muscle and producing airway inflammation.

It's important to realize that allergies aren't the cause of asthma, but rather are triggers of bronchial obstruction. Allergic reactions in the bronchial tube not only trigger asthma but also cause airway inflammation. Patients with asthma and allergies usually have a family history of allergies and asthma. This suggests that allergies, or the tendency to have allergies, is inherited. The precise role of genetic factors in allergies is not yet fully understood.

Goals of Asthma Therapy

The purposes of asthma therapy include treating the acute episode of asthma and preventing future asthma attacks. This demands combating bronchospasm and airway inflammation.

For asthma patients with allergies, an important goal of therapy is to reduce the likelihood of allergic reactions. This is often accomplished by eliminating the allergen(s) from the patient's environment. Some examples include removing dust-catching carpeting and drapes from bedrooms, and separating the asthmatic person from cats or dogs.

Since it's often impractical or virtually impossible to remove all allergens from the environment, patients must take regular medications to minimize allergic reactions. This prevention concept is very important to the good care of people with asthma. Following this philosophy can go far to allow people with asthma to lead normal, productive, and often unrestricted lives.

From W.W. Busse, M.D., "What is Asthma?", *Advance Plus* (May/June 1990), Asthma and Allergy Foundation of America: Washington, DC.

Why This Information is Important for the Health Paraprofessional

If you're working with individuals who have asthma, they will have medications that you may be asked to store. Individuals may come into your office having asthma problems involved with breathing. Make sure you have an Emergency Care Plan in place, as with the student with allergies. You will need to be able to quickly support their needs and get their medication ready. You should know the individuals who have asthma concerns in your building and keep it on record.

Case Study

Susan is sixteen and a sophomore in high school. This year during volleyball season she had an asthma attack for the first time. She went to the doctor and discovered she has asthma. She was taught how to use an inhaler and now needs to use it during the school day, thus she carries it with her all the time. Because the inhaler is a new concept to her and because she is a little nervous about the whole idea of having asthma, she is having some difficulties using the inhaler properly or at the correct times. One of her teachers notices this and sends her to your health office to discuss this with you. You ask her about her usage and she tells you she takes as many puffs as she thinks she needs, and is often nervous when she uses the inhaler so she breathes very quickly. She seems to be pretty "panicky" about the whole apparatus (the inhaler). What will you tell her? How will you calm her down?

Meet in a small group to discuss this. Then get together in the whole class group and discuss the solutions from your group.

Section 3

Attention Deficit Hyperactive Disorder

The American Psychiatric Association publishes the Diagnostic and Statistical Manual of Mental Disorders (DSM) which is used by medical and associated professionals for diagnosing disorders such as specific learning disabilities, mental retardation, and autism. Beginning in 1990, the DSM III-R contains a new definition of Attention Deficit Disorder (ADD), now referred to as Attention Deficit Hyperactivity Disorder (ADHD). The essential features of ADHD are developmentally inappropriate degrees of inattention, impulsiveness, and hyperactivity. People with the disorder generally display some disturbance in each of these areas, but to varying degrees.

Manifestations of the disorder usually appear to varying degrees in most situations, including at home, school, work, and in social situations. Some people, however, show signs of the disorder in only one setting, such as at home or at school. Symptoms typically worsen in situations requiring sustained attention, such as listening to a teacher in a classroom, attending meetings, or doing class assignments or chores at home. Signs of the disorder may be minimal or absent when the person is receiving frequent reinforcement or very strict control, is in a novel setting or a one-to-one situation (e.g., being examined in the clinician's office, or interacting with a video game)

In the classroom or workplace, inattention and impulsiveness are evidenced by not sticking with tasks sufficiently to finish them and by having difficulty organizing and completing work correctly. The person often gives the impression that he or she is not listening or has not heard what has been said. Work is often messy, and performed carelessly and impulsively.

Impulsiveness is often demonstrated by blurting out answers to questions before they are completed, making comments out of turn, failing to await one's turn in group tasks, failing to heed directions fully before beginning to respond to assignments, interrupting the teacher during a lesson and interrupting or talking to other children during quiet work periods.

Hyperactivity may be displayed by difficulty remaining seated, excessive jumping about, running in the classroom, fidgeting, manipulating objects and twisting and wiggling in one's seat.

At home, inattention may be displayed in failure to follow through on others' requests and instructions and in frequent shifts from one incomplete activity to another. Problems with impulsiveness are often expressed by interrupting or intruding on other family members and by accident prone behavior, such as grabbing a hot pan from the stove or carelessly knocking over a pitcher. Hyperactivity may be evidenced by an inability to remain seated when expected to do so (this situation varies greatly from home to home) and by excessively noisy activities.

With peers, inattention is evident in failure to follow the rules of structured games to listen to other children. Impulsiveness is frequently demonstrated by failing to await one's turn in games, interrupting, grabbing objects (not with malevolent intent) and engaging in potentially dangerous activities without considering the possible consequences, e.g., riding a skateboard over extremely rough terrain. Hyperactivity may be shown by excessive talking and by an inability to play quietly and to regulate one's activity to conform to the demands of the game (e.g., in playing "Simon Says," the child keeps moving about and talking to peers when he or she is expected to be quiet).

The DSM III-R diagnostic criteria for ADHD/is as follows:

- A A disturbance of at least six months during which at least eight of the following are present:
 - 1 Often fidgets with hands or feet or squirms in seat (in adolescents, may be limited to subjective feelings of restlessness).
 - 2 Has difficulty remaining seated while required to do so.
 - 3 Is easily distracted by extraneous stimuli.
 - 4 Has difficulty awaiting turn in games or group situations.
 - 5 Often blurts out answers to questions before they have been completed.
 - 6 Has difficulty following through on instructions from others (not due to opposition behavior or failure of comprehension)

e.g., fails to finish chores.

- 7 Has difficulty sustaining attention in tasks or play activities.
- 8 Often shifts from one incomplete activity to another.
- 9 Has difficulty playing quietly.
- 10 Often talks excessively.
- 11 Often interrupts or intrudes on others, e.g., butts into other children's games.
- 12 Often seems not to listen to what is being said to him or her.
- 13 Often loses things necessary for tasks or activities at school or home (e.g., toys, pencils, books, assignments).
- 14 Often engages in physically dangerous activities without considering possible consequences (not for the purpose of thrill seeking), e.g., runs into street without looking.

Please note the above items are listed in descending order of discriminating power based on data from a national field trial of the DSM III-R criteria for disruptive behavior disorders.

Additionally, consider a criteria met only if the behavior is considerably more frequent than that of most people of the same mental age.

B Onset before the age of seven.

C Does not meet the criteria for a Pervasive Developmental Disorder.

Criteria for Severity of Attention Deficit Hyperactivity Disorder

- **Mild:** Few, if any symptoms in excess of those required to make the diagnosis and only minimal or no impairment in school and social functioning.
- **Moderate:** Symptoms of functional impairment intermediate between "mild and severe."
- **Severe:** Many symptoms in excess of those required to make the diagnosis and significant and pervasive impairment in functioning at home and school, and with peers.

Drawn from the *Diagnostic and Statistical Manual of Mental Disorder* (third edition, revised), American Psychiatric Association: Washington, DC. 1987.

Why This Information is Important for the Health Paraprofessional

Many students who are classified ADHD are on medication to help them concentrate in the classroom. You will probably be the person administering the medications during the school day, so you may see the student at least once a day. You will need to understand that some of the behaviors exhibited in your office are a result of the condition

and be prepared to handle them as such. You may also be called on to observe the effectiveness of medication.

Case Study

Fred is eleven years old and in the sixth grade. He has difficulty in academics because he has a specific learning disability affecting his ability to follow directions and sequence. He also is on medication for ADHD. He needs to come to your office every day before lunch to take his medication. This has become a real problem for both you and the classroom teachers because Fred cannot remember to come in on his own. As a result, you or a classroom teacher or paraprofessional are tracking Fred down daily to remind him. This often creates frustration on your part and anger on Fred's part. You meet with the classroom team to come up with a plan to help Fred become more independent and responsible for taking his medication at the correct time. Assume you're with a small group developing a plan for Fred. What will you suggest as the health paraprofessional? Get together in a small group and discuss a plan for Fred. Then discuss your plan with the class.

Section 4

Cerebral Palsy

Cerebral palsy is a condition caused by damage to the brain, usually occurring before, during, or shortly after birth. "Cerebral" refers to the brain and "palsy" to a disorder of movement or posture. It's neither progressive nor communicable. It's also not "curable" in the accepted sense, although education, therapy, and applied technology can help persons with cerebral palsy lead productive lives. It's not a disease and should never be referred to as such. It can range from mild to severe.

Between 500,000–700,000 Americans have some degree of cerebral palsy. About 3,000 babies are born with the disorder each year, and another 500 or so acquire it in the early years of life. The causes of cerebral palsy include illness during pregnancy, premature delivery, or lack of oxygen supply to the baby. It may occur early in life as a result of an accident, lead poisoning, illness, child abuse, or other factors. Chief among the causes is an insufficient amount of oxygen reaching the fetal or newborn brain. The oxygen supply can be interrupted by premature separation of the placenta, an awkward birth position, labor that goes on too long or is too abrupt, or interference with the umbilical cord. Other causes may be associated with premature birth, RH or A-B-O blood type incompatibility between parents, infection of the mother with German measles or other viral diseases in early pregnancy, and

micro organisms that attack the newborn's central nervous system. Lack of good prenatal care may also be a factor.

A less common type is acquired cerebral palsy: head injury is the most frequent cause, usually the result of motor vehicle accidents, falls, or child abuse.

Characteristics

There are three main types of cerebral palsy: spastic, stiff, and difficult movement; involuntary and uncontrolled movement; and ataxia, disturbed sense of balance and depth perception. There may be a combination of these types for any one individual. Other types do occur, although infrequently.

Cerebral palsy is characterized by an inability to fully control motor function. Depending on which part of the brain has been damaged and the degree of involvement of the central nervous system, one or more of the following may occur: spasms; tonal problems; involuntary movement; disturbance in gait and mobility; seizures; abnormal sensation and perception; impairment of sight, hearing or speech; and mental retardation.

Developmental, Educational, and Employment Implications

Early identification of cerebral palsy can lessen developmental problems and lead to appropriate intervention when it helps the most. Early intervention programs are family-centered in which professionals and families work together with the child in specific activities. Educators, physical and occupational therapists, social workers, speech language pathologists, psychologists and physicians can assist families by providing information and education.

Activities for children with cerebral palsy may include:

- Speech and language therapy
- Occupational therapy
- Physical therapy
- Medical intervention
- Family support services
- Early education
- Applied technology

As a child gets older and begins formal schooling, the intensity of services will vary from individual to individual. Persons with cerebral palsy are usually able to attain a substantial degree of independence but, in some cases, may need considerable assistance. Services for the school-age child may include continuing therapy, regular or special education, counseling, technical support, community integration opportunities, recreation and possibly personal attendants. A key factor seems to be a supportive family.

People with extensive involvement can often be highly functional and independent. The HEATH Resource Center, the Clearinghouse for Higher Education and Adult Training for people with Handicaps, states that a significant number of students with cerebral palsy are enrolled in colleges and universities.

Important advances have taken place in the last fifteen years which have had a great effect on the long-term well-being of children born with cerebral palsy. Advanced technology has been applied to the needs of persons with cerebral palsy, including computers and engineering devices. Technological innovations have been developed in the areas of speech and communication, self-care, and adapting living arrangements and work sites. The future may bring even more significant applications.

Another important development has been the increased ability of persons with disabilities, including those with cerebral palsy and other severe disabilities, to live independently in the community. Independent living opportunities include group shared and supervised apartments, or living in the community with appropriate support services. Independent living centers have proven to be important resources for persons with disabilities.

Adapted from a fact sheet by National Information Center for Children and Youth with Disabilities: Washington, DC.

Why This Information is Important for the Health Paraprofessional

Paraprofessionals in the health office may see individuals with cerebral palsy to administer medications, or work with teams on appropriate accommodations in the classroom. You may also be called upon, with the school health nurse, to work with an occupational therapist or adaptive physical education specialist to help plan appropriate programs for the individual. Depending on the extent of involvement, the individuals with cerebral palsy may need no assistance from you for regular support with medication or toilet care.

Case Study

Mike, age ten, considers himself to be like the other children — only with a slight inconvenience: he has cerebral palsy. His condition exhibits itself in a speech impediment, spasms in his back and neck that cause his head to jerk to the back and side, and knocked knees and a swing gait which require him to use crutches to walk.

As a school health paraprofessional, what are some tasks you may assist Mike in completing? Mike participates in adaptive physical education; list possible activities in which he may be involved.

Section 5

Childhood Cancer

Cancer is really a number of diseases caused by the abnormal growth of cells. Normally, cells that make up the body divide and reproduce in an orderly manner, so that we can grow, replace worn-out body tissue, and repair injuries. Sometimes, however, cells get out of control, divide more than they should, and form masses known as *tumors*.

Some tumors may interfere with body functions and require removal, but don't spread to other parts of the body. These are known as *benign* tumors. *Malignant*, or cancerous tumors not only invade or destroy normal body tissue, but, by a process known as *metastasis*, break cells away from the original tumor which then go to other parts of the body where they may form additional malignant tumors.

Children with cancer have a better chance of living a long life than ever before. The survival rates range from more than 55% for children with bone cancer to almost 87% for children with Hodgkin's disease, a cancer of the lymph system.

Cancer is the main cause of death from disease among children from age one to fifteen. Only accidents cause more deaths among children. Each year, cancer will occur in about 7,800 children and cause 1,500 deaths, one third of them from leukemia. In the past forty years, however, the rate of deaths from childhood cancers has dropped by close to sixty percent. These gains are due to research finding new, better, and often less harsh ways to treat cancer. By working as a team, doctors, nurses, other medical care givers, and the child's own parents can keep the child in the best health possible while treating the disease.

Signs and Symptoms

There are several types of cancer that tend to occur in children. The most common are listed first.

Leukemia

Leukemia is a cancer that starts in the body tissues that make the blood, mainly the bone marrow – the soft, spongy center of bones. The most common form of leukemia occurs in children from ages two to six, and mainly in boys.

In a healthy body, worn-out blood cells are always being replaced by newly matured cells. The bone marrow also contains some immature cells. In leukemia, abnormal white blood cells, many of them immature, can crowd out the normal cells in the marrow and then overflow into the bloodstream. Because these white cells aren't mature, they cannot carry out their basic pur-

pose, which is to fight infection. In addition, because so many of these abnormal cells are being produced, the bone marrow cannot make enough normal white cells to fight infection and enough red blood cells to carry oxygen to other parts of the body. This means that a child with leukemia is more likely to get infections and have anemia, a shortage of red blood cells. The child is more likely to have blood loss because there's also a shortage of the platelets that control clotting and prevent hemorrhaging (bleeding that is hard to control).

The early symptoms of leukemia are much like those for colds and flu. The child may look pale, have a fever and loss of energy and appetite.

Neuroblastomas

Neuroblastomas are cancers of the nervous system and the fourth most common form of childhood cancer. The average age children develop neuroblastomas is two. Neuroblastomas are made up of very young and immature nerve cells and can occur anywhere in the body, but usually in the abdomen. The first sign of the disease may be a swelling in that area. In most cases, by the time the cancer is diagnosed it has already spread to the bone, bone marrow, liver, or lymph nodes. For this reason, most children with neuroblastomas seem quite sick at the time of diagnosis. They may have lost weight and be growing more slowly, seem to lack interest, be cranky, and have diarrhea, fever, and pain in the abdomen.

Brain Tumors

Brain tumors, even in their early stages, can cause headaches, blurred or double vision, and dizziness. The child may also have a hard time walking or handling objects. Brain tumors can spread to the spine, but rarely spread beyond the nervous system.

From Facts on Childhood Cancer, American Cancer Society, Inc.

More About Leukemia

Leukemia is a cancer of the blood and develops in the bone marrow, the body tissue that produces blood cells. The bone marrow is a jelly-like substance that fills the inside of the bones.

In speaking about leukemia, "blast" is the short name used for lymphoblasts, the immature white blood cells. There are normal blasts and leukemia blasts. Normally, blasts compose less than five percent of the cells made by the bone marrow and grow to form mature white blood cells with certain typical features visible under the microscope. Leukemia blasts are abnormal because they remain immature and don't function like mature white blood cells. In many cases, they look different from normal blasts when viewed under a microscope.

As the leukemia blast cells accumulate in the bone marrow, they begin to crowd out the normal blood cells that develop there. Eventually, they take up so much room that red blood cells, platelets, and normal white blood cells cannot be produced.

When that happens, the young person develops symptoms indicating that normal blood cells aren't being manufactured in adequate numbers:

- If red blood cells are crowded out by leukemia cells, the blood will look thin, which makes the patient look pale. The young person also may be tired, because the thin blood can not carry enough oxygen to the heart, lungs, and muscles.
- If blood platelets are crowded out in the bone marrow, the young person may have bleeding problems and unusual bruising.
- If the normal, mature kind of white cells known as neutrophils are crowded out by the blasts, there will be no cells to combat bacteria, and infections may occur.

In some cases, leukemia blasts may spill over from the bone marrow into the blood, where they can be seen by microscopic examination. This may cause a rise in the number of white cells in the blood (the white blood cell count). In other cases, blasts appear in the blood, and the white cell count doesn't change much. When leukemia blasts are present in the blood, they may be carried to other places in the body and enter various body organs where they may grow as well as in the bone marrow.

Kinds of Leukemia in Young People

Leukemia is not just one disease. There's actually a type of leukemia for each of the three major kinds of white blood cells – *neutrophils*, *lymphocytes*, and *monocytes*.

Leukemia in any one person can affect only one kind of blood cell. The most common kinds of leukemia are lymphocytic (also called lymphoblastic or lymphoid) and myelogenous (also called granulocytic, myelocytic, myeloblastic, or myeloid). Other types (monocytic, myelomonocytic, progranulocytic, or erythro leukemia) are very rare, but still act much like the more common kinds.

If leukemia affects a young person quickly, it's called "acute" because it comes on suddenly and progresses rapidly without treatment. Almost all childhood leukemias are acute, but the disease is sometimes of the "chronic" type. In chronic leukemia, the bone marrow is able to produce a good number of normal cells as well as leukemic cells so that, compared to acute leukemia, the actual disease course is milder for a period of time. Even without treatment, the disease usually progresses more slowly.

Acute Lymphocytic Leukemia

Acute lymphocytic leukemia (ALL) is commonly known as

childhood leukemia. It's the most common leukemia among the young and is the most commonly occurring cancer in children. As its name suggests, it affects the lymphocytes. Most children are between two and eight years old when diagnosed, but the disease can occur in people in their twenties and thirties as well. For reasons yet to be understood, slightly more boys get ALL than girls, and it occurs more frequently among white children than black children.

Acute Myelogenous Leukemia

Acute myelogenous leukemia (AML) is also called acute granulocytic leukemia. It usually occurs in people over twenty-five, but is sometimes found in teenagers and children. In AML, the leukemia blasts develop from the stem cells that would normally give rise to neutrophils. The characteristics of the blasts in AML are generally similar to those of acute lymphocytic leukemia, but special tests can be done to help determine whether a leukemia is myelogenous or lymphocytic.

Chronic Myelogenous Leukemia

Chronic myelogenous leukemia (CML) is not common in children. CML's distinguishing feature is the presence of very large numbers of immature neutrophil cells, which seem to mature more efficiently than blast cells. The progression of CML varies greatly, sometimes changing to a type of acute myelogenous leukemia.

Diagnosis and Treatment

Diagnosis of leukemia requires blood tests and examination of the cells in the bone marrow, because early symptoms can mimic many other diseases including mononucleosis, anemia arising from other causes, tonsillitis, rheumatic conditions, meningitis, mumps, and other kinds of cancer.

In any acute leukemia, it's necessary to determine which type of white blood cell has become leukemia, because treatment and response to it are different for each kind. The type of leukemia cell involved can usually be determined from its appearance under the microscope, but sometimes special tests of the chromosomes and cell chemistry are needed for complete certainty. In rare instances, the cells are too young to be classified. Such cases are called acute stem cell leukemia or acute undifferentiated leukemia (AUL). Other tests such as X-rays and lumbar puncture may also be undertaken to determine if areas other than the bone marrow are involved.

The primary treatment for leukemia is combination chemotherapy, where two or more anti cancer medications are used to control or eradicate the disease. Radiation, platelet and red cell transfusions, antibiotic therapy, and occasionally surgery (for un-

usual complications) are also a part of many treatment programs. In some forms of leukemia, marrow transplantation is attempted.

Adapted from *Young People with Cancer: A Handbook for Parents*, Office of Cancer Communications, National Cancer Institute and National Candlelighters Foundation, March 1988.

Why This Information is Important for the Health Paraprofessional

As a health paraprofessional, you may notice symptoms that appear to be similar to those listed here and should notify the school health nurse or parents when required to do so. Additionally, if you're working with an individual who has cancer, you need to know the background information about the condition and the individual's personal condition in order to be supportive to the individual and his or her family.

Section 6

Congenital Heart Disease

Congenital heart disease is a condition where a baby is born with a defect in the structure of the heart, surrounding blood vessels, or both. There are more than one hundred fifty different types of congenital heart disease. Some types of heart defects cause obvious problems such as causing the child's skin to look blue. Other heart defects are more difficult to find.

There are a variety of causes for congenital heart disease. The baby's heart develops early in pregnancy and begins to take shape in the third week of development. Many heart defects develop when the heart is being formed, early in pregnancy. Some heart defects are hereditary. Others are caused at birth when expected changes in blood circulation don't occur. Doctors are usually unable to find a direct cause of congenital heart disease.

Symptoms

The symptoms of congenital heart disease vary depending on the size and type of defect. Most children have no symptoms and grow and exercise normally. Some infants and children with heart problems may tire easily, grow at a slower rate, or have a bluish color to their skin, especially when they cry. Some types of congenital heart defects have more severe symptoms than other types. This often depends on the type and size of the defect. Many heart defects cause no apparent symptoms. Children with mild problems often don't need to have surgery to correct the problem.

Health Care with Children from Birth to Age Two

- Infants and toddlers with congenital heart disease sometimes must be hospitalized for surgical repair of the heart or blood vessels. During this time it helps the child adjust if parents are present as much as possible for comfort and support. Hospital staff support parents' decisions about how much time they spend with their child. Many hospitals that care for infant have open visiting hours for family members.
- The child's growth and development should be carefully monitored because some infants tire when feeding and don't eat enough.
- Watch for respiratory infections.
- Assistance can be given in planning to bring the child home from the hospital. If the child needs home care, hospital staff can help make arrangements.
- The child needs the same routine checkups and immunizations that all children need.

Development

- Children develop faster as infants and toddlers than at any other time in life. Most children with congenital heart disease will grow and develop at a normal rate. However, children with some types of heart problems may lack the energy for moving around and seem to have slowed development. The child's development may improve after surgery.
- Some infants get tired quickly and don't drink enough milk to grow. Those babies may need to be fed every two to three hours for a long time if they aren't gaining enough weight.
- Provide a safe environment that allows the child to play with the least restriction. Provide toys and activities that are right for the child's age.
- All children are better able to manage life if they feel good about themselves. It's important to begin building self-esteem early by praising the infant or toddler often.
- After the heart is repaired, expect the same behavior from the child with congenital heart disease as from other children. Set appropriate limits on the toddler's behavior. Children who aren't feeling well may regress in their behavior at times. They may want people to do things for them that they previously did themselves. However, these children have the same needs for love and discipline as other children.

School

- Most children with congenital heart disease will not need special education services. Children with delayed development and special health care needs may be eligible for Early Inter-

vention services which provide services to children birth to age three. In this program, parents are partners in a multidisciplinary team that makes an Individual Family Service Plan (IFSP).

Day Care

- Most children with congenital heart disease can attend regular day care. They usually don't require different care from other children.

Health Care with Children Ages Three to Five

Health Care

- Continue regular health care.
- Children with congenital heart disease need antibiotics prior to having dental care or other surgical procedures. Taking antibiotics before procedures such as cleaning the teeth prevents bacteria from entering the bloodstream and lodging in the heart. If the child doesn't take antibiotics, there's a possibility that heart valves could be damaged by bacteria from the mouth. Health professionals refer to this treatment as *bacterial endocarditis prophylaxis*.

Development

- Provide the child with simple information about congenital heart disease.
- Provide the child with opportunities to do the following:
 - Play with other children of the same age
 - Learn to start and complete activities when playing.
 - Have a balance between structured activities and free time to play.
 - Succeed, so the child gains self-confidence.
- Children who aren't feeling well may regress in their behavior at times. However, these children have the same needs for love and discipline as other children.

School

- Most children with congenital heart disease will not need special education services. Children with delayed development and special health care needs may be eligible for Early Childhood Special Education. In this program, parents are partners in a multidisciplinary team that makes an Individual Educational Plan for the child.
- If the child has any special restrictions on activity, parents should discuss them with the teacher and the school nurse who should relay the information to you.

Health Care with Children Ages Six to Twelve

Health Care

- Continue regular health care.
- Children of this age are generally very active. If the child has special restrictions on activity, parents should ask the child's doctor for guidance in planning an exercise program and relay that information to the teacher(s) and school nurse. Most children don't need to adjust their activity because of a congenital heart condition.

Development

- School-age children understand factual information about congenital heart disease. Give them specific information about their condition in response to their questions. Also, encourage them to talk to their doctor about their condition, and to read about it on their own too.
- Allow the child increasing control over diet and medications. Encourage them to relay to you their needs for medication and diet instead of you asking them.
- Encourage the child to be responsible for remembering when to take medications. Mastering self-care skills will give a child self-confidence and a feeling of accomplishment.

School

- Parents should meet with the child's teachers and the school nurse at the beginning of each year to keep them informed of changes in the child's condition and treatment.
- Children with congenital heart disease usually don't miss more school than their peers. Arrange for homework to be sent home when the child is absent. If the child is absent from school for more than fifteen days, homebound services can be requested. A child is also eligible for homebound services sooner than fifteen days if he or she is absent frequently or the doctor expects the absence to last more than fifteen days.
- Encourage the child to be involved in group activities for children his or her age.

Health Care with Children Ages Thirteen to Seventeen

Health Care

- Continue regular health care.
- Remind the teenager about the benefits of exercise for developing muscles and increasing endurance.

Development

- Some teens with congenital heart disease may enter puberty later than their peers. Reassure the teen that he or she will mature physically, but possibly at a slower rate than other adolescents.
- Independence is necessary for teenagers to develop responsible behavior. Responsible behavior will usually follow independence, if teenagers understand the benefits and consequences of their actions.
- Teens need to understand if congenital heart disease will affect their sexual and reproductive life. They may need encouragement to ask questions. Discuss any specific concerns with the youth and encourage him or her to discuss concern with his or her doctor.
- Smoking is harmful to the health of anyone who smokes, but even more harmful to the teen who has a congenital heart problem.
- Using illicit drugs and alcohol can be especially dangerous to a person with a congenital heart condition. Some drugs can cause an irregular heart beat (*arrhythmia*) or bacteria in the blood (*bacteremia*).
- Peers become increasingly important to teenagers. Teens with high self-esteem can resist peer pressure. They will also be less concerned about being different from their friends.

School

- Encourage the youth to advocate for him- or herself in school. Teens can keep school staff informed of their needs. At some time during adolescence, most teens will resist advocating for themselves. During this time, other family members may need to keep school staff informed of any health care needs.

Health Care with Children Ages Eighteen to Twenty-one

Health Care

- Continue regular health care.
- If the young adult moves away from home, plan ahead for his or her health care. Some young adults find it helpful to find a doctor in the new area before moving. The family doctor may be able to refer the young person to a specialist in the new area.
- When the young adult moves away from home or gets a job, encourage him or her to find out if the current health insurance coverage continues. Some insurance policies will cover young adults only if they attend school as a full-time student. Discuss health insurance needs with the individual, as requested and needed.

Development

- Young adults focus on life goals, education, and careers at this age. Having a congenital heart defect doesn't usually limit career possibilities.

School

- When they move away to school, young adults may want to plan for regular follow-up visits for cardiac problems. Students often continue to see their cardiologist when they visit home.

Adapted from materials provided by the Minnesota Department of Health, Minneapolis, MN.

Why This Information is Important for the Health Paraprofessional

If you're working with an individual with a heart condition, it's important to know what kinds of physical activity restraints the individual must observe as well as the medication, schedule of medication, and diet modification the individual must observe. Talk to the school nurse and the individual about his or her health history, read the records, and ask the parents. Come up with a schedule and a plan for meeting the individual's needs based on this information.

Section 7

Cystic Fibrosis

Cystic fibrosis (CF) is an inherited digestive and pulmonary disorder and is the most common fatal genetic disease in the United States today: CF, a disease which shows no sexual preference and doesn't affect mental ability, affects approximately 30,000 children and young adults. It occurs in approximately one of every 2,500 live births. Approximately 1,300 new cases are diagnosed each year, usually within the first three years of life.

One in twenty Americans – more than twelve million people – is an unknowing, symptomless carrier of the defective gene. Both parents must be carriers of the CF gene for their child to have the disease. Each time two carriers conceive a child, there's a twenty-five percent chance that the child will have CF, a fifty percent chance that the child will be a carrier, and a twenty-five percent chance that the child will be a non-carrier.

The basic defect in CF is created by the faulty transport of sodium chloride (salt) from within the epithelial cells, which line the surfaces of organs such as the lungs and pancreas, to their outer

surfaces. The sweat test is currently the only reliable diagnostic test for cystic fibrosis. This simple, painless test measures salinity of the sweat: a high level indicates that a person has CF.

The pace of cystic fibrosis research accelerated when the CF gene was discovered in 1989. In 1990, scientists successfully made copies of the normal gene and added them to CF cells in the laboratory which corrected the defective cells. The next major step toward gene therapy is now underway: CF researchers, with the continued support of the Cystic Fibrosis Foundation, are refining new gene transfer technology that will lead to a cure.

Symptoms

CF has a variety of symptoms. The most common are salty-tasting skin; persistent coughing, wheezing or pneumonia; excessive appetite but poor weight gain; and bulky foul-smelling stools.

CF disturbs the functions of the exocrine (outward secreting) glands of the body. The mucus produced by the exocrine glands in the lungs is normally thin, slippery and clear. In individuals with CF, this mucus is thick and sticky. It clogs breathing passages and, if not removed, can lead to recurrent lung infections and lung damage. Treatment to help bring up the abnormal mucus often includes bronchial drainage and inhalation of aerosol medications and antibiotics.

Digestion

The thick CF mucus also obstructs parts of the pancreas, preventing enzymes from reaching the intestine to digest food. Without treatment, the body doesn't absorb enough nutrients. Fortunately, the digestive disorders of CF can be helped by ingesting supplementary enzymes and following a special diet low in fat and high in protein, supplemented by extra vitamins, antibiotics, and salt tablets.

Sweat

The sweat of individuals with CF is extremely high in salt. (CF is diagnosed by testing the sweat's salt content.) Individuals with CF may lose a lot of body salt in their sweat, and may actually form salt crystals on their skin.

Treatment

The treatment of cystic fibrosis depends upon the stage of the disease and which organs are involved. One means of treatment, postural drainage (also called chest physical therapy or CPT), requires vigorous clapping on the back and chest to dislodge the thick mucus from the lungs. This can also be done by wearing a special vest to do percussing; the SHP may see these in school. Antibiotics are also used to treat lung infections and are adminis-

tered by pills and/or medicated vapors which are inhaled to help open clogged airways.

Cystic Fibrosis in the Classroom

If an individual in the classroom has cystic fibrosis, you may be puzzled about the disease and apprehensive about how this individual will affect the classroom. Since cystic fibrosis affects each person differently, it's impossible to clearly define the physical health and emotional attitude of the individual with CF. Individuals with CF have the same emotional needs as other children, but group acceptance may be more important to them because this disease makes them feel different. A frequent complaint from young adults with CF is that they're sometimes regarded as "diseased" people rather than as individuals with feelings, hopes, and potential.

The severity of CF varies from person to person, even within the same family. The physical condition of the individual with CF is generally fair to good, allowing him or her to attend school on a full or part time basis. At the other extreme are those individuals with CF whose condition is so severe they can't regularly go to school.

Although there's no cure for the disease, the outlook for individuals with CF has improved dramatically in recent years because of better methods of treatment. Many now live beyond age eighteen. Thus, the average individual with CF can expect to attend high school and to continue his or her education – and life – into young adulthood.

Individuals with CF may cough frequently – and should not be discouraged from doing so. Since CF is not contagious, this coughing is not spreading germs which would cause other children to develop the disease. Some people with CF may feel embarrassed by their coughing: help them feel more comfortable by making it easy for them to slip out of the classroom for a "drink of water". Many children have been taught to expectorate the mucus into a tissue. Paying undue attention to a student's coughing will likely cause other students to do the same. Remember that students often follow the lead of their teacher. Thus, if the teacher accepts his coughing as not that unusual, his or her classmates will think the same.

Physical activity within one's tolerance also helps clear the mucus from the lungs. The planning team, including the nursing staff and parents should consider the individual's limitations when determining his or her physical education grade. Exercise is not only healthy but also provides a psychological boost by promoting feelings of group membership. Include him or her in all games and activities in which he or she is physically able to participate without becoming overly exhausted.

People with CF are particularly susceptible to contagious res-

piratory infections. Thus, in bad weather or during a respiratory epidemic, parents may decide to keep children with CF at home. In the classroom, you can help safeguard students with CF from exposure to other children who have cold symptoms.

From materials from the Cystic Fibrosis Foundation, Bethesda, Maryland.

Why This Information is Important for the Health Paraprofessional

As the school health paraprofessional, you may be called upon to help the individual with cystic fibrosis expectorate the mucus that he or she needs to expel continually. You may need to work with younger individuals to help them learn good hygiene during this process. You may also be called upon to help administer medications throughout the day.

There are striking variations in the severity of the disease. Therefore, treat each individual who has CF as an individual case. The LSN will discuss students' needs with their families and develop plans (IHPs) for you to follow. The individual's physician may have special recommendations. If the individual is unable to attend school regularly, perhaps arrangements can be made for part-time participation or home instruction.

CF is often misdiagnosed as pneumonia, chronic bronchitis, asthma, or malnutrition. If you work with an individual showing CF's special combination of signs (frequent cough, recurrent pneumonia, unusual appetite, frequent bowel movements, small stature and enlarged fingertips), notify the school physician so that the pupil can be tested for CF.

Section 8

Diabetes

Diabetes is a disease that affects the way the body uses food, causing sugar levels in the blood to be too high. About fourteen million Americans have diabetes.

During digestion, the body normally changes sugars, starches, and other foods into a form of sugar called glucose. Then the blood carries this glucose to cells throughout the body where, with the help of insulin (a hormone), glucose is changed into quick energy for immediate use by the cells or is stored for future needs. (Insulin is made in the beta cells of the pancreas, a small organ that lies behind the stomach.) This process is crucial because the body depends on food for every action.

In diabetes, something goes wrong with the normal process of turning food into energy. Food is changed into glucose readily

enough, but there is a problem with insulin. In one type of diabetes, the pancreas can't make insulin. In another type, the body makes some insulin but either makes too little or has trouble using it (or both). When insulin is absent or ineffective, the glucose in the bloodstream cannot be used by the cells to make energy. Instead, glucose collects in the blood, eventually leading to the high sugar levels that are the hallmark of untreated diabetes.

Types of Diabetes

The two main types of diabetes are *insulin-dependent* and *non-insulin-dependent*.

Insulin-dependent (type I) diabetes used to be called *juvenile-onset diabetes* because it occurs most often in children and young adults. But the name was changed after doctors realized it could occur at any age. In this form of diabetes, which affects more than one million people, the pancreas stops making insulin or makes only a tiny amount. Insulin is necessary to life, so the hormone must be injected every day.

Non-insulin-dependent (type II) diabetes used to be called *maturity-onset diabetes* because it occurs most often in adults. In non-insulin-dependent diabetes, which affects almost thirteen million people, the pancreas produces *some* insulin but it's not used effectively. Unfortunately, an estimated six million people have non-insulin-dependent diabetes and don't know it. The people most at risk for this type of diabetes are over forty, overweight, and have a family history of diabetes.

There are other kinds of diabetes, but these are less common.

Gestational diabetes is high blood sugar that first occurs during pregnancy. It usually disappears after the birth of the baby, although nearly fifty percent of these women develop diabetes (usually non-insulin dependent) within five to ten years. *Secondary diabetes* is the type caused by damage to the pancreas from chemicals, certain medicines, or diseases of the pancreas (such as cancer) or other glands.

Impaired glucose tolerance used to be called *latent*, *chemical*, or *borderline diabetes* but is no longer considered to be a form of diabetes. Individuals with this diagnosis have blood sugar cells between "normal" and "diabetic" levels. People with impaired glucose tolerance have an increased risk of developing diabetes.

Symptoms

The following symptoms are typical. However, some people with non-insulin-dependent diabetes have symptoms so mild that they go unnoticed.

Insulin-dependent Diabetes

The symptoms of insulin dependent diabetes usually occur

suddenly. They include:

- Frequent urination
- Excessive thirst
- Extreme hunger
- Dramatic weight loss
- Irritability

Non-insulin-dependent Diabetes

The symptoms of non-insulin-dependent diabetes usually occur less suddenly. They include:

- Any of the insulin dependent symptoms
- Recurring or hard-to heal skin, gum, or bladder infections
- Weakness and fatigue
- Drowsiness
- Nausea and vomiting
- Blurred vision
- Tingling or numbness in hands or feet
- Itching

Prevention and Treatment

The causes of diabetes are still a mystery, but researchers believe that the tendency for diabetes is present at birth. In insulin-dependent diabetes, any of several different viral infections and a process called *autoimmunity* are believed to trigger diabetes. In the autoimmune process the body's defense system attacks its own cells, the insulin-producing beta cells in the pancreas. Note that although viruses may help to cause some cases of insulin-dependent diabetes, diabetes is not contagious. In people prone to non-insulin-dependent diabetes, being overweight can cause diabetes, because excess fat prevents insulin from working properly.

So far, insulin-dependent diabetes can't be prevented, although researchers are working on many promising approaches. Insulin dependent diabetes is treated with daily insulin injections, regular exercise, and a balanced meal plan that limits sugar. Such a meal plan will be tailored to the individual's needs and is likely to include three meals and two or three snacks a day at set times each day to properly balance insulin, which is also given at fixed times. (Insulin lowers blood sugar, and food raises it: to control diabetes, you need to balance these effects.)

Non-insulin-dependent diabetes can often be prevented by maintaining normal body weight and keeping physically fit throughout life. A major aim of treatment is to control blood-sugar levels, which means keeping them in the normal range. Research suggests that tight control can help prevent or delay long-

term diabetic complications. Non-insulin-dependent diabetes is treated with an individualized diet plan that restricts calories. If you're overweight, you need to slim down. Treatment also includes restricting sugar and following an exercise plan. These steps should improve your body's ability to use its insulin. If diet and exercise alone don't control blood sugar, prescribed pills or insulin may be needed.

Testing

Two types of tests are used to monitor blood-sugar levels: blood tests and urine tests. Blood tests, done by pricking the finger for a drop of blood, are recommended by most doctors because they give the exact amount of blood sugar at any given moment. Urine test readings are a crude indication of blood sugar, and are much less direct and much less precise. People with insulin-dependent diabetes are often advised to test sugar levels two to four times a day, before and after meals. People with non-insulin-dependent diabetes may be able to test less often. Tests that measure ketones in the urine are also important. Ketones are acids that collect in the blood and urine when the body uses fat (instead of glucose) for energy. Ketones in the urine are a sign that diabetes is poorly controlled and that prompt attention is needed. Always test for ketones when you're ill or under great stress, the times when diabetes is likely to go out of control. Be sure to record the results of all your self-tests. These records are useful guides for adjusting food, medicine, or exercise when blood sugar is too high or low. Another important test, done by a doctor every three to six months, is a "glycohemoglobin" test. This measures the average blood-sugar level over the past thirty to sixty days.

Problems to Handle Promptly

Hypoglycemia

Hypoglycemia, low blood sugar, is sometimes called an *insulin reaction* or *insulin shock*. It can occur suddenly in people using insulin if too little food is eaten, if a meal is delayed, or if extra exercise is done. It's less common in people whose diabetes is treated with pills but can occur. Low blood sugar must be treated quickly, with sugar or sugary foods because, when untreated, hypoglycemia can lead to unconsciousness. The typical symptoms include feeling cold, clammy, nervous, shaky, weak, or very hungry. Some people become pale, get headaches, or act strangely. If a person becomes unconscious, glucagon, a hormone (available by prescription) that raises blood sugar, must be injected.

Hyperglycemia

Hyperglycemia, or high blood sugar, occurs when too much food is eaten or not enough insulin is taken. Illness and emotional

stress can also cause high blood sugar. The warning signs are large amounts of sugar in the urine and blood. You may also urinate often, be very thirsty, and feel nauseated. Treat high blood sugar with the help of your doctor.

Ketoacidosis

Ketoacidosis, or diabetic coma, may accompany high blood sugar. It develops when insulin and blood sugar are so out of balance that ketones accumulate in the blood. High levels of ketones are poisonous. Fortunately, ketoacidosis, which develops over several hours or days, can usually be avoided if diabetes is brought under control at the first signs of high blood sugar or ketones in the urine. (Call the doctor for instructions.) In addition to high blood and urine sugar levels and high ketone levels, the symptoms include dry mouth, great thirst, loss of appetite, excessive urination, dry and flushed skin, labored breathing, fruity smelling breath, and possible vomiting, abdominal pain, and unconsciousness. Ketoacidosis is most likely to occur in people with insulin-dependent diabetes. Anyone with diabetes should wear a medical ID necklace or bracelet stating the type of treatment they use in case of emergencies.

Long-Term Health Problems

Diabetic complications are usually caused by changes in the blood vessels and nerves. Unfortunately, they can include eye and kidney disease, heart attack, numbness or pain in the legs, foot infections leading to gangrene, and stroke. Fortunately, however, treatments continue to improve. Also, many researchers now believe that keeping blood-sugar levels tightly controlled from the moment of diagnosis can help to prevent complications. Excellent control is especially important for diabetic women who want to become pregnant, because tight control from before conception helps to prevent birth defects.

Adapted from information from the American Diabetes Association, Diabetes Information Service Center, Alexandria, VA.

Why This Information is Important for the Health Paraprofessional

The individual with diabetes will be seen in the health office for several reasons. The most common is blood sugar testing. Most individuals learn how to do their own blood sugar testing, if they are able, and the health paraprofessional only is there to take out the medication and supervise. Individuals may come in if they need to check their blood sugar and eat quick snack. Most individuals who are able to learn to monitor their own needs and are efficient at asking for what they need to regulate themselves.

Case Study

Joe was diagnosed with diabetes at age two. At fifteen, he's a sophomore this year. His daily routine at school is to snack mid-morning and do a glucometer test. He does the same just prior to physical education class to insure that his blood sugar is stable. Joe's blood sugar tends to fluctuate, however, so that on any given day, he may need to come to the health office. He usually comes with a "buddy" from class because it's better for him to have someone accompany him due to symptoms of "low" blood sugar. For Joe, these symptoms are shakiness, headache, and blurred vision. A blood sugar check confirms his symptoms. He then immediately eats a fast-acting sugar, such as gluco-tablets, followed by a snack such as cheese and crackers. He then he re-checks his blood sugar in fifteen to twenty minutes. If it's returning to his normal range, he feels better, but needs to eat something substantial, such as milk and a sandwich, or lunch if it's lunchtime.

This is Joe's daily routine. He needs to self-manage and "read" his body experience at all times in order to manage his diabetes. To assist him, the school nurse developed an Emergency Care Plan to inform school staff about his diabetes, his symptoms (when his blood sugar is "low") and then a plan of action.

It's important to remember that diabetes is a lifetime condition and that students need support, understanding, and encouragement.

Pretend you're the health paraprofessional at Joe's high school. You're particularly sensitive and supportive: Joe has responded to your attitude with a very positive outlook himself. Because you have such a good relationship with Joe, the school health nurse has asked you to develop some ideas for a new Emergency Care Plan for Joe for this school year. In the space provided below, write down the main points that will have to be in his plan, baser on his needs. Make a tentative schedule for Joe. Be prepared to explain why you made the plan the way you have and be ready to discuss it with the class.

Section 9

Eating Disorders

Approximately six in 1,000 young women suffer from anorexia nervosa. Persons with anorexia nervosa may be young or old, black or white, rich or poor, female or male.

Bulimia nervosa is more common than anorexia nervosa, and it's believed that at any point in time five to ten percent of females between twelve and twenty-four years of age display significant bulimic behaviors. Although bulimia tends to develop in late ado-

lescence and early adulthood, it can occur at any age. It's important to note that at least forty percent of people with anorexia nervosa also suffer simultaneously from bulimia.

Most individuals with bulimia are women, but this eating disorder does occur in men: ten to twenty percent of adolescents with eating disorders are male.

Individuals who are at risk tend to display some or all of the following traits: one's self-esteem based on weight; constant thoughts about "feeling fat"; repeated attempts to diet; self-consciousness or embarrassment about eating; compulsive exercising; isolation; perfectionism; eating for emotional comfort; over-achieving; limited emotional expression; and ritualistic behavior around food. There are also numerous physical problems individuals with eating disorders may display:

- Cessation of menstruation; loss of sexual interest
- Chronic kidney problems
- Irregular heart rhythms
- Irritation and tears in the esophagus
- Parotid gland swelling (under jaw-line)
- Erosion of tooth enamel and increased cavities
- Electrolyte imbalance
- Growth of lanugo (fine hair on body surface)
- Muscle cramps
- Light-headedness and dizziness or fainting
- Unusual sensitivity to cold
- Dry skin and thinning scalp hair
- Stomach and intestinal problems
- Unexplained swelling (edema)
- Chronic constipation and other colon problems.

There are numerous similarities between anorexia and bulimia, including a preoccupation with dieting, food, weight, and body size; discomfort when eating with others; severe changes in habits, mood, and personality; hyperactivity; difficulty with concentration and sleep; complaints of fatigue, headaches, edema, and paresthesia; approval-seeking behaviors; and problems with interpersonal relationships.

Despite these similarities, there are equally significant differences between the two disorders. Individuals with anorexia tend to be introverted and preoccupied with losing more and more weight; deny any abnormal eating behavior; turn away food to cope; and have a distorted body image. Individuals with bulimia are frequently extroverted and preoccupied with attaining an ideal, unrealistic weight; recognize abnormal eating patterns; turn to food to cope; and experience dissatisfaction with body weight and shape.

Anorexia Nervosa

Anorexia nervosa is an emotional disorder characterized by severe weight loss (or failure to gain weight in young people). Individuals with anorexia nervosa have an unyielding determination to become thin, and an intense, irrational fear of becoming fat, both of which often increase as weight is lost. In lay terms, anorexia nervosa involves "dieting gone wild".

Persons with anorexia nervosa vigorously refuse to maintain a healthy weight. Weight is lost through a variety of methods, including severe caloric restrictions, fasting, relentless exercising, use of over-the-counter diet aids, diuretic and laxative use, and, in some cases, self-induced vomiting. Most individuals suffering from anorexia nervosa strongly deny the disorder in part because they often "feel fat" even when they are very thin. Moreover, they experience a sense of control by restricting food intake and often turn away from food in an attempt to cope with life's stresses.

Symptoms of Anorexia Nervosa

- Abnormal weight loss of ten percent or more with no known medical illness accounting for the loss.
- Restriction (reduction) of food intake.
- Denial of hunger and/or the problem.
- Decrease in the consumption of foods containing animal fats.
- Intense fear of weight gain and/or a "grim determination" to become thinner and thinner.
- Abnormal reproductive functioning; i.e., amenorrhea in women, low testosterone levels in males.
- Prolonged exercising despite fatigue and weakness.
- Peculiar patterns of handling food.
- Distorted perception of weight, body-size and/or shape.
- Inability to control weight-loss and amount of exercise.
- Social withdrawal.
- Unusual sensitivity of the cold.
- Perfectionism paired with a profound sense of ineffectiveness.
- Weight loss through use of vomiting, diuretics, and/or laxatives.
- Lanugo (fine hair on body surface), symptoms of starvation.

Bulimia Nervosa

Bulimia nervosa is an emotional disorder which consists of episodes of binge eating followed by some form of purging and/or severe dietary restraint. A "binge" is the secretive consumption of large amounts of food in a short period of time. Most bulimics

follow the binge by self-induced vomiting, but "purging" may take the form of laxative or diuretic abuse, fasting, abuse of diet pills, or strenuous exercise. This binge-purge cycle is normally accompanied by self-depreciating thoughts, depressed mood, and an awareness that the eating behavior is abnormal and out of control.

In most cases the binge-purge cycle is an outlet for feelings of frustration, disappointment, anger, loneliness, or boredom. In this regard bulimia nervosa may be accompanied by other impulsive behaviors such as shoplifting, self-injury, and/or the abuse of alcohol and other drugs. It's also important to note that a person can be anorexic and bulimic at the same time.

Symptoms of Bulimia Nervosa

- Fear of weight gain.
- Distinct and often uncontrollable, secretive episodes of binge eating followed by attempts to purge the food through self-induced vomiting.
- Unhealthy dieting and/or use of laxatives, diuretics, or diet aids.
- Depression and recurrent mood swings.
- Prolonged exercise for the purpose of weight control.
- Inability to discontinue the binge-purge cycle.
- Problems with the throat, esophagus, stomach, and colon.
- Edema and swelling of the parotid glands.
- Dental problems.
- Emotional instability and impulsivity.
- Dissatisfaction with body shape and preoccupation with becoming thin.
- Frequent weight fluctuations.

Supporting Someone with an Eating Disorder

Living and working with a person who has an eating disorder is a very difficult and trying experience. If you're close to someone you suspect has an eating disorder, you may want to consider some of these suggestions which may minimize the discomfort and help resolve the problem.

Don't make comments about the individual's food intake, eating habits, or weight. Make sure she or he is under a physician's care, and contact the parent and/or physician with any concerns you have. Parents aren't responsible but may feel very guilty. The illness is very complex, and no one person or event caused it. Once the individual's physical condition has been checked out, encourage that he or she get psychotherapy; then getting well becomes their responsibility. Step back and allow them to be responsible for their own recovery. Neither you nor the family can "fix" or make

them well.

Recognize that the individual's behavior is likely to cause parents to feel helpless and angry. Most families of children with eating disorders find that coping with the child's illness is anger-provoking and frightening. Recognize and accept these feelings. However, rather than expressing them to the individual, it's suggested that you encourage the family and the individual to seek counseling or a support group.

In conflicts about decisions, parents should not retreat from their own positions out of fear that their child will become increasingly ill. As an outside support, you should maintain a supportively confident posture in dealing with the child. This is not to suggest that harshness, rigidity, or anger need to be used, but rather that you be consistent and caring.

Support the individual by expressing honest interest toward her or him through verbal and physical expression. Do not put them down by comparing them to more "successful" students or friends. Their self-esteem is a reflection of others' esteem for them. Affirm them for who they are, rather than for their accomplishments, performance, or looks. They are constantly looking for praise or criticism in these areas – don't get hooked into giving it.

Do everything you can to encourage the individual's initiative, independence, and autonomy. Trust them to find their own values, ideals, and standards as they approach adulthood. They have a lot of fears about becoming independent and parents and other adults are often reluctant to encourage this process.

Tips for Helping a Person Who May Have an Eating Disorder

- Encourage progress, not perfection.
- Encourage responsibility and accountability for actions.
- Avoid driving individuals to excel beyond their capabilities.
- Medically necessary weight changes should be supervised under a physician's care.
- Exert caution in commenting on appearance.
- Communicate love and care regardless of weight.
- Collect information about anorexia and bulimia and about local sources for treatment or support. Keep a file of this information in the health office. A good place to begin is your local mental health association or health professional.
- In a caring and non-judgmental way, tell the person what you have observed in the way of anorexic or bulimic behavior. Suggest they seek physical and psychological assessment by a qualified professional. Give the individual the phone number and name of a treatment source.
- If the person is a minor, discuss your observation with LSN,

teachers, or guidance counselors (check your community's law and regulations). As a paraprofessional, you should first discuss your concerns with your supervising health nurse. Do not promise to keep the eating disorder a "secret."

- If the individual and/or the parents deny there is a problem, consult with supervisors who will discuss treatment resources, children's services, or local health services for what to do next. Be patient, and let the individual know you are both concerned and available for further consultation.
- When a person begins treatment, be natural and caring with them, but don't discuss eating, weight, or appearance. Do not insist that the person eat or change attitudes. Become involved in activities and discussions with them that don't center around food and weight issues.

Information in this section was adapted from fact sheets developed by Fairview Riverside Mental Health Services, Minneapolis, MN.

Why This Information is Important for the Health Paraprofessional

A student with an eating disorder will often come into the health office complaining of related ailments. At first glance, the ailments may not seem to be related to an eating disorder, but the astute health paraprofessional who can piece together a series of complaints may be able to determine that the real problem is an eating disorder. Another important reason for the health paraprofessional to be informed about eating disorders is to serve as a resource to other staff who may have concerns about students. It would be valuable to have a file of information similar to the information above to share with concerned parents or staff. Because eating disorders are so prevalent, you will want to know the basic characteristics.

Case Study

A fourteen year old girl is referred to the health office in her middle school because the teacher is concerned about her. Alice is in the teacher's English class just after lunch each day. To the teacher, she seems preoccupied with dieting but at the same time is very thin. She complains everyday of headaches and fatigue. She is a very good student and is a perfectionist about her work. She becomes very upset if she makes any mistakes. She's on the track team and is a long distance runner. When Alice comes in, you recognize her as a student you have seen in the office for a variety of small ailments that never seem to "amount to anything". On receiving the teacher's referral, you begin to piece some facts together and think maybe Alice has an eating disorder. How will you handle this with Alice? Who should you consult with? What immediate action should you take? What long range plans should you

make or suggest? Get together in a small group and discuss some ideas. Has anyone in the group had such an experience? Come back to the larger class group with your suggestions as a team.

Section 10

Emotional/Behavioral Disorders

Individuals who behave in ways that significantly interfere with their learning and with developing positive relationships with others are often found to have a disability called an emotional/behavioral disorder, or E/BD. These individuals usually have low self-esteem and poor social skills – that is, they haven't learned appropriate behaviors to get along with others. They may have some learning disabilities but are often very bright and capable.

There are several types of emotional/behavioral disorders:

- **Aggression:** Physical or verbal behaviors meant to hurt others.
- **Disruptiveness:** Behaviors that disrupt the classroom, i.e. getting out of seat, making noises, throwing objects, talking out, and interrupting.
- **Noncompliance:** Uncooperativeness with requests and suggestions and unwillingness to follow directions. Individuals with attention deficit hyperactivity disorder (ADHD) often demonstrate some of these behaviors.
- **Temper Tantrums:** Characterized by acting-out behaviors including crying, stamping, throwing self, screaming, kicking, clinging, jumping up and down, shouting, pounding, etc. Tantrums are most often found with toddlers and young children.
- **Stereotypic Behavior:** Repeated actions or responses that may be self-injurious or self-stimulatory. These behaviors are most commonly observed in children who are autistic or severely mentally disabled.

Childhood depression, anxiety disorders, fears and phobias, obsessive compulsive disorders, and schizophrenia are also included with E/BD.

Causes of E/BD

Almost anything can cause E/BD behaviors. The four main factors that interact to influence behavior are biology, family, school, and culture. E/BD type behaviors may be triggered by environmental stresses and/or incidents that are seen as threatening by the individual. For example, an individual may feel frustrated with an assign-

ment or task, but instead of asking for help he or she may act-out or shut down. These individuals often try to get attention through negative behaviors such as acting like the class clown, "smarting off", or simply refusing to do work. These are behaviors they have learned: don't expect them to "know better". They need to be taught the appropriate behaviors. It's important to keep in mind that the individual may have feelings of fear, discomfort, anger, humiliation, self-hatred, and despair. They need support and encouragement.

Tips for Helping an Individual with E/BD

- Be proactive!
- Give the individual choices.
- Listen; be patient.
- Give warnings about events (so he or she will know what to expect).
- "Catch individuals being good" and/or following rules and praise them!
- Rearrange the environment to prevent problems.
- Find strengths and emphasize them; build self-esteem!
- Help match individuals up with a potential friend.
- Let the individuals be useful and helpful to you.
- Use a problem-solving method. (See the section "Behavior Assistance/Crisis Intervention Team" below.)

There are also a variety of things to stay away from when working with an individual with E/BD:

- Reacting: you need to stay calm and in control.
- Using a loud voice: this will only increase the problem. Use a soft but firm tone and respectful language.
- Saying things like, "No, you can't."
- Getting into power struggles and arguing with the individual. (This is what the individual may be used to and arguing is a lose-lose situation).
- Physical struggles: unless the individual is hurting themselves or others, avoid touching or holding. It's important to give the individual some space and time to regain self-control. If a restraint is necessary, a gentle but firm basket hold may be used.
- Finally, you should keep in mind that these individuals have a hidden but very real disability. They should be treated with respect, understanding, and great care. They aren't to blame for their E/BD behavior. Know that, anything you do to be proactive will make a tremendous difference in these individuals' lives!

Adapted by Karen Kozen from T.J. Zirpoli & K.J. Melloy. *Behavior Management: Applications for Teachers and Parents*. Columbus, Ohio: Merrill/Macmillan, 1993.

Behavior Assistance/Crisis Intervention Team

These are steps for developing a problem solving plan:

- 1 De-escalate the individual. Be calm and personalize situation:
"I care about you (individual's name) as a person and a learner, I'm here to help you solve the problem."
- 2 Identify the behavior: "What did you do?"
- 3 Make a value judgment: "Is it helping you?" "Is it helping others?" "Is it against a rule?"
- 4 Work out a plan: "What can you do differently?"
 - Alternate behavior
 - Discuss appropriate behavior choices
 - Give rationale for appropriate behavior
 - Practice appropriate behavior (i.e., give scenario and role play)
- 5 Make a commitment: "Will you do this?" Sign a contract.
- 6 Explain both rewards and consequences for future behavior choices.
- 7 Write apologies, enabling the student to return to classroom with a "clean slate".
- 8 Praise the student for cooperation; plan a time for checking in as follow-up for the plan.

Adapted from William Glasser's "seven steps to effective discipline" model: "Teaching Interaction Steps for Inappropriate Behavior and Crisis Intervention" by Kris Melloy, Ph.D.: from materials developed by Karen Kozen: and from T.J. Zirpoli & K.J. Melloy. *Behavior Management: Applications for Teachers and Parents*. Columbus, Ohio: Merrill/Macmillan, 1993.

Why This Information is Important for the Health Paraprofessional

Paraprofessionals working in the health office may see individuals with emotional or behavioral disorders. They may enter with a condition that is related to their behavior for which they need medication, such as ADD or ADHD, or they may need assistance as a result of an injury related to an outburst. For whatever reason you may have encounters with individuals with E/BD, you will need to know how to appropriately react and treat these individuals. This section give you background and a problem solving technique to help work with individuals who may have E/BD.

Case Study

Jonathan, who is eight years old, frequently comes to see the SHP in the health office with various "emergency" situations. Today he came into the office with another third grader after activity period. The other child says, "This bully is always picking on me," and each

child has superficial abrasions. This is the third time this week Jonathan has been involved in an incident like this. As a SHP, what actions would you take?

Section 11

Epilepsy

According to the Epilepsy Foundation of America, epilepsy is a physical condition that occurs when there's a sudden, brief change in how the brain works. When brain cells aren't working properly, a person's consciousness, movement, or actions may be altered for a short time. These physical changes are called *epileptic seizures*. Epilepsy is therefore sometimes called a seizure disorder. Epilepsy affects people in all nations and of all races.

About two million Americans have epilepsy. Of the 100,000 new cases that develop each year, three quarters of them are in children and adolescents.

Some people can experience a seizure and not have epilepsy. For example, many young children have convulsions from fevers. These febrile convulsions are one type of seizure. Other types of seizures not classified as epilepsy include those caused by an imbalance of body fluids or chemicals or by alcohol or drug withdrawal. A single seizure doesn't mean that the person has epilepsy.

Symptoms

Although the symptoms listed below aren't necessarily indicators of epilepsy, it's wise to consult a doctor if someone you're working with experiences one or more of them:

- "Blackouts" or periods of confused memory.
- Episodes of unexplained unresponsiveness or staring.
- Involuntary movement of arms and legs.
- "Fainting spells" with incontinence or followed by excessive fatigue.
- Odd sounds, distorted perceptions, episodic feelings of fear that can't be explained.

Educational Implications

Students with epilepsy or seizure disorders are eligible for special education and related services under the Individuals with Disabilities Education Act (IDEA). Epilepsy is classified as "other health impaired" and an Individualized Education Program (IEP) would be developed to identify appropriate services. Some students may have additional conditions such as learning disabilities.

Seizures may interfere with the individual's ability to learn. If the individual has the type of seizure characterized by a brief period of fixed staring, he or she may be missing parts of what the teacher or supervisor is saying. It's important that the teacher or supervisor observe and document these episodes and report them promptly to family and nurses.

Depending on the type of seizure or how often they occur, some individuals may need additional assistance to help them keep up with others. Assistance can include adaptations in instruction, first aid instruction on seizure management to those that teach or work with the individual, and counseling, all of which should be written in the IEP.

It's important that teachers and school staff be informed about the individual's condition, effects of medication, and what to do in case a seizure occurs. Most family members find that a friendly conversation with teachers at the beginning of the school year is the best way to handle the situation. Even if an individual has seizures that are largely controlled by medication, it's still best to notify those teaching or working with the individual about the condition.

School and work personnel and the family should work together to monitor the effectiveness of medication as well as any side effects. If an individual's physical or intellectual skills seem to change, it's important to tell the doctor. There may also be associated hearing or perception problems caused by the brain changes. Written observations of both the family and school staff will be helpful in discussions with the individual's doctor.

Children and youths with epilepsy must also deal with the psychological and social aspects of the condition. These include public misperceptions and fear of seizures, uncertain occurrence, loss of self-control during the seizure episode, and compliance with medications. To help individuals feel more confident about themselves and accept their epilepsy, the school or work environment can assist by providing epilepsy education programs for staff or workers and students, including information on seizure recognition and first aid.

Individuals can benefit the most when the family, work and school are working together.

From General Information about Epilepsy, National Information Center for Children and Youth with Disabilities (NICHY), Washington, DC.

First Aid for Seizures

About Seizures

There are many types of seizures – some more common than others. It's important that a person's seizure type be accurately identified so that a physician may, if necessary, prescribe the

proper anti-convulsant medication and provide guidance suitable to the person's condition and life-style.

Seizures can be *generalized*, meaning that all brain cells are involved. One type of generalized seizure consists of a convulsion with a complete loss of consciousness. Another type looks like a brief period of fixed staring.

Seizures are *partial* when those brain cells not working properly are limited to one part of the brain. Such partial seizures may cause periods of "automatic behavior" and altered consciousness. This is typified by purposeful looking behavior, such as buttoning or unbuttoning a shirt. Such behavior, however, is unconscious, may be repetitive, and is usually not recalled.

Among the seizure types seen most frequently are generalized tonic-clonic (grand mal) seizures, complex partial seizures, and absence (petit mal) seizures. In each of these types, the person experiencing the seizures loses consciousness either completely or partially. Properly administered first aid, where needed, can be very helpful.

Remember that there's no way to stop a seizure once it has started. The person's medication will not help: the seizure must be allowed to run its course. The principal reason for first aid measures is to keep the person from suffering any injury. Do not be concerned if, in a tonic-clonic seizure, the person cries out; he or she isn't in pain: the sound is a result of withheld air rushing out of the lungs.

Above all, stay *calm*. Your reassurance will be a comfort when the seizure is over. If the person has a series of seizures in quick succession without regaining consciousness or if a tonic-clonic seizure lasts more than five to ten minutes, a doctor should be called or the person should be taken to a hospital staffed and equipped to manage this situation.

Recognizing Generalized Tonic-Clonic (Grand Mal) Seizures

Symptoms of the tonic phase include:

- Sudden loss of consciousness
- Falling
- Involuntary outcries
- Muscle stiffening
- Temporary loss of ability to breathe

Symptoms of the clonic phase include:

- Alternate periods of muscle spasm and relaxation
- Possible cheek or tongue biting with bleeding
- Foamy salivation
- Cessation of breathing for a few seconds (the person may turn slightly blue)

The usual length of a tonic-clonic seizure is one to three minutes.

Characteristics of the post-seizure phase include:

- Resumed breathing
- Regained consciousness
- Temporary confusion and/or sleepiness
- Possible vomiting or loss of bladder or bowel control

What You Can Do to Help During or After a Seizure

- Try to cushion falls.
- Help the person to a lying position, preferably on his or her side to keep the airway open.
- Change the person's position by pushing or pulling the body trunk, not the limbs, because shoulder dislocations may sometimes occur.
- Remove any eyeglasses.
- Loosen tight clothing.
- Place something soft or a pillow under the head.
- Remove furniture or other objects from the immediate area.
- If possible at the beginning of a seizure (but *only* at the beginning), remove any dentures or other removable dental work.
- Don't try to restrain the individual's movement. The seizure will run its course. Attempts to restrain movement may cause injury.
- Remain with the person. Don't leave to get help – your presence may be necessary. It will be reassuring when the person awakens.
- *Never force anything into the mouth.* Attempting to pry apart firmly closed jaws may cause more injury than the seizure itself.
- Assist the individual's breathing. If the person is lying on his or her back, turn the person on his or her side after the convulsions have stopped. This will allow the tongue to return to its normal position, if it has fallen toward the throat and blocked breathing. It will also permit accumulated saliva to drain from the mouth. Do not attempt to clear the person's airway; breathing returns on its own as the seizure passes.
- Discourage premature activity. Don't try to make the person swallow liquids during the seizure or immediately afterwards: there's a possibility of choking. Don't rush the person into standing or walking while the post-seizure confusion remains. The person will eventually get up without encouragement.

Complex Partial Seizures

Symptoms of Complex Partial Seizures (Psychomotor, Temporal Lobe)

- Confusion, impaired awareness of surroundings; aimlessness.
- "Automatic" movements (pacing, hand rubbing, picking at clothing, lip smacking, or chewing motions).
- Possibly drunk or drugged appearance.
- Person may struggle if restraint is attempted.
- Lasts two to four minutes.
- May progress to generalized seizures.

First Aid Measures

- Stay with the person.
- Guide gently to protect from injury.
- Do not attempt to impede movements, as the person may struggle or fight.
- Let seizure run its course.
- Remain with person until consciousness is fully recovered.
- Let person rest or sleep until he or she feels well again.

Absence Seizures

Symptoms of Absence (Petit Mal) Seizures

- Very short; end rapidly.
- Few seconds of lost consciousness; often mistaken for day-dreaming.
- Possible staring, eye blinking, or facial twitching.
- Person doesn't generally fall.
- Person has no awareness of episode.
- Most common in children ages six to fourteen.

First Aid Measures

None are needed, but the person's physician should be notified of the seizure's occurrence.

From First Aid for Epileptic Seizures: A Guide for Parents, Teachers, and Friends, Epilepsy Foundation of America, Information Service, 1992.

Why This Information is Important to the Health Paraprofessional

The health paraprofessional may be called upon to direct others or lead in first aid procedures during a seizure. The health office

should also be the place where information is kept on individuals who have seizures and their needs. Know the characteristics of the various types of seizures. It's very important for you as the para-professional to be familiar with the procedures in case of seizure and for you to be a *calm* and knowledgeable resource to others in the environment.

Case Study

Candy is a six year old who has seizures. When she entered first grade this fall, her parents sat down with the school health nurse and her teacher and explained Candy's needs. Candy's seizures are a result of an early childhood accident on the playground. She has petit mal seizures fairly frequently, but she handles them without anyone knowing, for the most part, that she has had a seizure. The teacher and staff need to know that her apparent inattentiveness, may, however, be the result of these seizure. Candy is able to monitor and maintain herself except when she is overly tired. Then she is much more likely to having grand mal seizures. The parent, the teacher, the school health nurse and you sit down to come up with an IHP to address Candy's needs. Make suggestions as to what you think should be included in that IHP. Do you have enough information? Are there additional questions you need to ask? Do other staff people need to be involved and/or informed about Candy? If so, who? Make suggestions in a small group about how you would address Candy's IHP. Be prepared to discuss your ideas in the larger group.

Section 12

Hemophilia

Hemophilia is a hereditary blood clotting disorder which occurs most often in males, although a few cases have been diagnosed in females. It's caused by the inactivity or absence of one of several blood proteins necessary for clotting. There are about 20,000 males with hemophilia in the United States, an estimate which doesn't include many mild cases that remain undiagnosed until patients experience excessive bleeding after major trauma or surgery. Hemophilia occurs in one out of every 4,000 live male births. This population is expected to continue to grow, as medical advances have enabled the person with hemophilia to approach a normal life expectancy. It affects people of all races, nationalities, and economic levels. The prevalence of von Willebrand's disease, which occurs in males as well as females, may be as high as that for hemophilia.

A male with hemophilia cannot pass the disease on to his sons.

However, all of his daughters will be genetic carriers and can pass hemophilia on to succeeding generations. Women may carry the gene for hemophilia, but rarely have symptoms of the disease: mothers with apparently normal clotting ability may pass hemophilia on to their sons. In most instances, there's a known family history of hemophilia. As many as one third of newly discovered cases, however, have occurred in families without a history of this disorder. Von Willebrand's disease and other clotting disorders have different patterns of inheritance.

Hemophilia is classified by its level of severity – mild, moderate, and severe, which in turn is determined by the percentage of active clotting factor in the blood. Persons with severe hemophilia have less than one percent of the normal level of active clotting factor present in their blood.

The clotting disorders included in the term hemophilia are Hemophilia A (Classical Hemophilia, Factor VIII deficiency), and Hemophilia B (Christmas disease, Factor IX deficiency), and Von Willebrand's disease. Other rare clotting disorders may have similar symptoms, but aren't usually termed hemophilia. All of these disorders are included within programs of The National Hemophilia Foundation.

What Happens When a Person with Hemophilia Bleeds?

A person with hemophilia or Von Willebrand's disease doesn't bleed faster than anyone else, but may bleed for a longer time. Contrary to common opinion, people with hemophilia don't bleed to death from minor external wounds. Minor cuts are easily treated, much as they are in the person without hemophilia.

The major problem for the person with hemophilia is uncontrolled internal bleeding which can begin spontaneously without apparent cause. If internal bleeding is not quickly stopped with appropriate treatment, it will result in pain and swelling. Over a period of time, bleeding into joints and muscles can cause permanent damage leading to chronic pain and arthritis.

Treatment

The person with hemophilia is treated each time he or she experiences internal bleeding by infusing a clotting factor derived from human blood. This infused clotting factor stops the bleeding but remains active in his blood for less than a day. More serious bleeding episodes require repeated infusions of clotting factor until the bleeding is controlled. It's important to administer clotting factor as soon as internal bleeding begins in order to reduce the chances of permanent damage. Although there is effective treatment, there's presently no cure for hemophilia. A child born with the disease will have hemophilia throughout his life.

The treatment of hemophilia is expensive. The cost of blood products and other hemophilia related medical expenses varies from person to person. Studies have shown that the average cost to an individual is approximately \$10,000 a year. On occasion, complications of hemophilia, such as major surgery, have caused annual medical expenses to exceed \$100,000. The costs for safer and purer clotting factors now under development may increase treatment expenses.

Complications of Treatment

Hepatitis viruses can be transmitted by blood products, including clotting factor concentrates. These viruses lead to very mild chronic infections in most persons with hemophilia, but can progress to severe liver disease in some people.

During the early 1980s, most clotting factor became contaminated with the virus that causes acquired immunodeficiency syndrome (AIDS). As a result, many persons with hemophilia were exposed to this virus, termed Human Immunodeficiency Virus (HIV), and some individuals developed AIDS. The majority of persons with hemophilia have *not* contracted AIDS; however, the potential to develop the disease is still a major concern to those who were exposed to HIV in the early 1980s. Blood products available today are much safer because blood donors are screened, their blood is tested for evidence of HIV infection, and products are heat treated to destroy any virus which might not have been detected. For those who weren't exposed to HIV, these safety measures have eliminated the risk of infection from clotting factors.

Advances in the Treatment of Hemophilia

Beginning in the 1960s, the treatment of hemophilia radically changed when clotting factors became available in concentrated form. Improved treatment continued through the 1970s, with development of comprehensive care in regionalized hemophilia treatment centers throughout the United States. As a result, the quality of life for the person with hemophilia has improved dramatically. People with hemophilia and their families have been taught to administer clotting factor at home, work, and school. Home therapy allows for early treatment and frees the patient and his family from complete dependence on the hospital. With adequate clotting factor and careful management, most people with hemophilia may safely undergo complex dental procedures and major surgery at hemophilia treatment centers.

Counseling and education have substantially enhanced the potential for people with hemophilia to lead independent and productive lives. Genetic counseling has expanded considerably due to these recent advances in genetic testing. Carriers of the hemophilia gene can now be detected with a high degree of certainty, and a fetus with hemophilia can now be identified early in pregnancy.

The advances in hemophilia care since the 1970s have led to dramatic human and economic benefits:

- 74% reduction in unemployment.
- 73% reduction in days lost from work or school.
- 83% reduction in hospitalization.
- 74% reduction in costs of care.

The National Hemophilia Foundation's goals for the future include finding a cure through research; improving the safety and efficacy of clotting factors; developing treatments for HIV and AIDS; providing optimal health care for hemophilia at lower costs; educating the public; and providing adequate psycho-social support to families.

Very recent advances in immunology and genetic engineering have resulted in highly purified and virus-free human and synthetic (recombinant-DNA produced) clotting factors which are now undergoing clinical testing. These new technology products are the first step toward a cure for hemophilia. Alternative treatment methods are being explored as well, such as the use of a synthetic hormone called DDAVP to treat some patients with von Willebrand's disease and mild hemophilia.

Adapted from materials by the National Hemophilia Foundation, New York, NY.

Why This Information is Important for the Health Paraprofessional

Persons with hemophilia may require special care from you, especially in the case of accidents during the day. Make sure you know who has this condition in your setting and what special care they may need.

Section 13

Lupus

Lupus is a chronic inflammatory disease that can affect various parts of the body, especially the skin, joints, blood, and kidneys. The body's immune system normally makes proteins called antibodies to protect the body against antigens – viruses, bacteria, and other foreign materials. In an autoimmune disorder such as lupus, the immune system loses its ability to tell the difference between antigens and its own cells and tissues. The immune system then makes antibodies directed against "self." These antibodies, called *auto-antibodies*, react with the "self" antigens to form immune complexes. The immune complexes build up in the tissues and can

cause inflammation, injury to tissues, and pain.

For most people, lupus is a mild disease affecting only a few organs. For others, it may cause serious and even life-threatening problems. More than 16,000 Americans develop lupus annually. Approximately 500,000 Americans have been diagnosed with lupus.

The idea that lupus is generally a fatal disease is one of the gravest misconceptions about this illness. In fact, the prognosis of lupus is much better today than ever before. Although there's currently no cure, current methods of therapy have made deaths from lupus very uncommon: up to ninety percent of people with lupus can live relatively normal lives for more than ten years after diagnosis. Most people with lupus rarely require hospitalization, especially if they follow their treatment plans.

Types of Lupus

There are three types of lupus: *discoid*, *systemic*, and *drug-induced*.

Discoid Lupus

Discoid lupus is always limited to the skin. It's identified by a rash that may appear on the face, neck, and scalp, and is diagnosed by examining a biopsy of the rash for abnormalities that aren't found in skin without the rash. Because discoid lupus doesn't generally involve the body's internal organs the ANA test, used to detect systemic lupus, may be negative in patients with discoid lupus. However, in a large number of patients with discoid lupus, the ANA test is positive, but at a low level or "titer."

In approximately ten percent of patients, discoid lupus can evolve into the systemic form of the disease, which can affect almost any organ or system of the body. This cannot be predicted or prevented. Treatment of discoid lupus will not prevent its progression to the systemic form. Individuals who progress to the systemic form probably had it at the outset, with the discoid rash as their main symptom.

Systemic Lupus

Systemic lupus is usually more severe than discoid lupus and can affect almost any organ or system of the body. For some people, only the skin and joints will be involved. In others, the joints, lungs, kidneys, blood or other organs and/or tissues may be affected. Generally, no two people with systemic lupus will have identical symptoms. Systemic lupus may include periods in which few, if any, symptoms are evident ("remission") and other times when the disease becomes more active ("flare"). Most often when people mention "lupus," they are referring to the systemic form of the disease.

Drug-induced Lupus

Drug-induced lupus occurs after the use of certain prescribed drugs. The symptoms of drug-induced lupus are similar to those of systemic lupus. The drugs most commonly connected with drug-induced lupus are hydralazine (used to treat high blood pressure or hypertension) and procainamide (used to treat irregular heart rhythms). However, not everyone who takes these drugs will develop drug-induced lupus. Only about four percent of the people who take these drugs will develop the antibodies suggestive of lupus. Of those four percent, only an extremely small number will develop overt drug-induced lupus. The symptoms usually fade when the medications are discontinued.

Causes of Lupus

The direct cause or causes of lupus is unknown, but there *are* environmental and genetic factors involved. Some of the environmental factors that may trigger the disease are infections, antibiotics (especially those in the sulfa and penicillin groups), ultraviolet light, extreme stress, and certain drugs.

Although lupus is known to occur within families, there's no known gene or genes which are thought to cause the illness. Only ten percent of lupus patients will have a close relative who already has or may develop lupus. Statistics show that only about five percent of the children born to individuals with lupus will develop the illness.

Lupus is often called a "woman's disease" despite the fact that many men are affected. Lupus can occur at any age, and in either sex, although it occurs ten to fifteen times more frequently among adult females than among adult males. The symptoms of the disease are the same in men and women. People of African, American Indian, and Asian origin are thought to develop the disease more frequently than Caucasians, but the studies that led to this result are small and need corroboration.

Hormonal factors may explain why lupus occurs more frequently in females than in males. The increase of disease symptoms before menstruation and/or during pregnancy supports the belief that hormones, particularly estrogen, may be involved. However, the exact hormonal reason for the greater prevalence of lupus in women, and the cyclic increase in symptoms, is unknown.

Symptoms

Although lupus can affect any part of the body, most patients experience symptoms in only a few organs. The table below is a list of the most common symptoms of people with lupus.

Symptom	Percentage
Achy joints (arthralgia)	95
Fever over 100° F (38° C)	90
Arthritis (swollen joints)	90
Skin rashes	74
Anemia	71
Kidney involvement	50
Chest pain on deep breathing (pleurisy)	45
Butterfly-shaped rash across the cheeks and nose	42
Photosensitivity	30
Hair loss	27
Raynaud's phenomenon (fingers are white/blue in cold)	17
Seizures	15
Mouth or nose ulcers	12

Flares

What triggers an attack of lupus in a susceptible person? For some, exposure to the sun causes sudden development of a rash and then possibly other symptoms. In others a cold or a more serious infection doesn't get better and then complications arise. These complications may be the first signs of lupus. In still other cases, a drug taken for some illness produces the signaling symptoms. In some women, the first signs develop during pregnancy. In others, they appear soon after delivery. Many individuals cannot remember or identify a specific factor. Obviously, many seemingly unrelated factors can trigger the onset of the disease.

People with lupus should learn to recognize early symptoms of disease activity to help their physicians know when a change in therapy is needed. Regular monitoring by laboratory tests can also be valuable because noticeable symptoms may occur only after the disease has significantly flared. Changes in blood test results may indicate the disease is becoming active even before the patient develops symptoms. Generally, the earlier such flares are detected the more easily they can be controlled. Early treatment may also decrease the chance of permanent damage and reduce the time one must remain on high doses of drugs.

Diagnosis

Because many lupus symptoms mimic those of other illnesses, are sometimes vague, and may come and go, lupus can be difficult to diagnose. Diagnosis is usually made by a careful review of the patient's entire medical history coupled with an analysis of the results obtained in routine laboratory tests and some specialized tests related to immune status. There's currently no single test to determine if a person has lupus. To assist the physician in the di-

agnosis of lupus, the American Rheumatism Association issued a list of eleven symptoms or signs that help distinguish lupus from other diseases (see the table below). A patient should have four or more of these symptoms to suspect lupus. The symptoms don't all have to occur at the same time.

Criterion	Definition
Malar Rash	Rash over the cheeks
Discoid Rash	Red raised patches
Photosensitivity	Reaction to sunlight, resulting in the development of or increase in skin rash
Oral Ulcers	Ulcers in the nose or mouth: usually painless
Arthritis	Nonerosive arthritis involving two or more peripheral joints
Serositis	Pleuritis or pericarditis
Renal Disorder	Excessive protein and/or cellular casts in the urine.
Neurologic Disorder	Seizures and/or psychosis in the absence of drugs or metabolic disturbances which are known to cause such effects.
Hematologic Disorder	Hemolytic anemia or leukopenia (white blood count below 4,000/mm ³) or lymphopenia (less than 1,500 lymphocytes/mm ³) or thrombocytopenia (less than 100,000 platelets/mm ³).
Note: <i>The leukopenia and lymphopenia must be detected on two or more occasions. The thrombocytopenia must be detected in the absence of drugs known to induce it.</i>	
Immunologic Disorder	Positive LE prep, anti-DNA, or anti-Sm test, or false positive syphilis test (VDRL).
Antinuclear Antibody	Positive test for anti-nuclear antibodies (ANA) in the absence of drugs known to induce it.

Testing

The first laboratory test devised was the LE (lupus erythematosus) cell test. Unfortunately, the LE cell test is not specific for systemic lupus: it can also be positive in up to twenty percent of patients with rheumatoid arthritis, in some patients with other rheumatic

conditions like Sjogren's syndrome or scleroderma, in patients with liver disease, and in persons taking certain drugs (such as procainamide, hydralazine, and others).

The immunofluorescent anti-nuclear antibody (ANA, or FANA) test is more specific for lupus. It's positive in virtually all patients with systemic lupus, and is the best diagnostic test for systemic lupus currently available. If the test is negative, the patient will likely not have systemic lupus. Yet because it *can* be positive in conditions other than lupus, the results of the ANA test have to be interpreted in light of the individual's medical history, as well as the current clinical signs and symptoms.

New tests, such as the anti-DNA antibody, anti-Sm antibody, anti-RNP antibody, and the anti-Ro antibody tests, have been developed which are very helpful in diagnosis.

Physicians will sometimes also perform skin biopsies of both the patient's rashes and his or her normal skin. These biopsies can help diagnose systemic lupus in about seventy-five percent of patients.

The interpretation of all these positive or negative tests, and their relationship to symptoms, is frequently difficult. A test may be positive one time and negative another time, reflecting the relative activity of the disease or other variables. When questions cannot be resolved, consult an expert in lupus.

When someone has many symptoms and signs of lupus and has positive tests for lupus, physicians have little problem making a correct diagnosis and initiating treatment. However, a more common problem occurs when an individual has vague, seemingly unrelated symptoms of achy joints, fever, fatigue, or pains. Some doctors may think the person is neurotic. Others may try different drugs in the hope of suppressing the symptoms. Fortunately, with growing awareness of lupus, an increasing number of physicians will consider the possibility of lupus in the diagnosis.

Treatment

For the vast majority of people with lupus, effective treatment can minimize symptoms reduce inflammation, and maintain normal bodily functions.

Preventive measures can reduce the risk of flares. For photosensitive individuals, avoiding excessive sun exposure and/or the regular application of sunscreens will usually prevent rashes. Regular exercise helps prevent muscle weakness and fatigue. Immunization protects against specific infections. Support groups, counseling, talking to family members, friends, and physicians can help alleviate the effects of stress. Needless to say, negative habits like smoking, excessive consumption of alcohol, too much or too little prescribed medication, or postponing regular medical checkups, are hazardous to people with lupus.

Treatment approaches are based on the specific needs and

symptoms of each person. Because the characteristics and course of lupus may vary significantly, it's important to emphasize that a thorough medical evaluation and ongoing medical supervision are essential to ensure proper diagnosis and treatment.

Medications are often prescribed for people with lupus depending on which organ(s) are involved, and the severity of involvement. Effective patient-physician discussions regarding the selection of medications, their possible side effects, and any changes in dosage are vital. Commonly prescribed medications include:

- **Non-Steroidal Anti-Inflammatory Drugs (NSAIDs):** These medications are prescribed for a variety of rheumatic diseases, including lupus. The compounds include acetylsalicylic acid (aspirin), ibuprofen, naproxen, indomethacin, sulindac, tolmetin, and others. These drugs are usually recommended for muscle and joint pain and arthritis. Aspirin may cause stomach upsets for some people. The other NSAIDs work in the same way as aspirin, but tend to be less irritating to the stomach and often require fewer pills per day to have the same effect.
- **Acetaminophen:** Acetaminophen (e.g., Tylenol) is a mild analgesic that can often be used for pain. It has the advantage of less stomach irritation than aspirin, but it's not nearly as effective at suppressing inflammation as aspirin.
- **Corticosteroids:** Corticosteroids (steroids) are hormones normally produced in small quantities by the adrenal gland that have anti-inflammatory and immunoregulatory properties. This hormone controls a variety of metabolic functions in the body. Because steroids have a variety of side effects, such as weight gain, acne, easy bruising, osteoporosis, high blood pressure, cataracts, increased risk of infection and stomach ulcers, the dose has to be regulated. Side effects occur more frequently when steroids are taken over long periods of time at high doses.
- **Anti-malarials:** Chloroquine (Aralen) or hydroxy chloroquine (Plaquenil), commonly used in the treatment of malaria, may also be very useful in some individuals with lupus. They are most often prescribed for skin and joint symptoms of lupus.
- **Cytotoxic Drugs:** Azathioprine and cyclophosphamide are in a group of agents known as cytotoxic or immunosuppressive drugs which act in a similar manner to the corticosteroid drugs. The side effects of these drugs include anemia, low white blood cell count, and increased risk of infection. Their use may also predispose an individual to developing cancer.

Nutrition and Diet

There have been suggestions about various foods and the treatment of lupus. However these diets have been used only in animals

with limited success and should not become the main stay of a patient's diet.

Information adapted from materials by the Lupus Foundation of America, Inc., Rockville, MD.

Why This Information is Important for the Health Paraprofessional

Individuals with lupus may need your support during the day if they have a flare up. You should also know the symptoms in case you begin seeing someone regularly complaining of symptoms that may be early signs of the disease.

Section 14

Neurological Impairments

The following information is given as background information to help in the understanding of any of a number of neurological disorders in which individuals may need special assistance from the health paraprofessional. The first part provides background information into the neurological evaluation. You may be in planning meetings where the neurological report on an individual is discussed: the first part of this chapter is designed to give you a better idea of what that report means.

The second section gives information about head injuries. Head injuries are highlighted here because people who have had head injuries resulting in disability related conditions are becoming more and more prevalent. As medicine continues to improve and people survive more accidents that would previously been fatal, survivors are re-entering schools and work needing special medical assistance.

The Neuropsychological Evaluation

The diagnosis of brain injury can frequently be aided by clinical neuropsychology, a branch of psychology which concerns itself with cognitive impairments from brain injury – impairments in thinking and reasoning, language processes, memory, attention, and organization of behavior.

Neuropsychological evaluation employs a wide range of objective tests designed to assess thinking and reasoning abilities (both verbal and non-verbal); memory; attention and concentration; the ability to understand and produce written and spoken language; and sensory motor abilities. Comparisons are made between the performances of groups of people with and without brain injuries

and patterns of impaired functioning can be identified. When these patterns make sense in terms of what is known about the workings of different areas of the brain, conclusions can be reached about probable brain damage and its location even when "hard" signs are lacking. The symptoms produced by the more diffuse, microscopic lesions of concussion are more difficult to interpret than those caused by severe localized brain injuries. Still, there may be a patterning or severity which strongly implies organic brain damage.

Signs of Brain Injury

The cognitive signs of organic brain injury are as diverse as the human mind itself. Frequently, there is impairment of memory of new events and also for intentions because the brain regions subserving these functions (in the temporal and frontal lobes) are extremely susceptible to injury due to bony protrusions inside the skull, no matter where the blow. Also common are difficulties with sustained concentration, and the person may become quite distractible and digressive in conversation. Language problems can also be seen as a difficulty in finding words, slowed or slurred speech, or problems in understanding conversation. Language difficulties usually suggest damage to left cerebral hemisphere. Other problems come about from damage to the right hemisphere. Right hemisphere injuries commonly involve problems in understanding spatial relationships, so that a person may not be able to build things, or draw simple representations, or may become easily lost in the environment.

A third class of problems affects the organization of behavior. Difficulties staying with a task, in making plans or in solving problems are often seen in frontal-lobe injuries. Sometimes a brain injury will show itself in emotional outbursts or in difficulty with tolerating frustration.

Treatment of Cognitive Problems

Until recently, it was believed that all brain damage is irreversible and that significant recovery or organic cognitive impairment was rare. Both of these beliefs have been challenged by recent research and by new developments in treatment. The brain, it appears, does possess remarkable abilities to recover after injury, and it can continue to recover over a period of many years. Part of the recovery seems to involve the reorganization of the brain to accommodate for lost function - intact areas taking over for damaged areas. Even re-growth of nerve tissue can occur under some conditions. Specific simulation and retraining appears to be essential in supporting these processes. Even where re-growth doesn't occur, helping an individual understand and compensate for lost abilities is beneficial, since the nature of a brain injury is often hidden from the individual's and the family's awareness.

A new treatment advance, emphasizing these principles, is cog-

nitive rehabilitation – a marriage of cognitive psychology, neurology, remedial education, and psychotherapy. Employing exercises to simulate arousal and concentration to prod and compensate for poor memory, to retrain thinking and problem solving, and to re-teach social skills, cognitive rehabilitation programs have helped many people with brain injuries return to more satisfying and useful lives.

Brain-injury treatment programs employing cognitive rehabilitation are just beginning to make an impact, and there are now several in various parts of the country. Many hospitals have outpatient rehabilitation services which accomplish similar purposes. Treating a person with a cognitive impairment from brain injury as if the main problem were depression or anxiety can only confuse an already confused person and add feelings of guilt and hopelessness to the existing problem. With increasing medical and legal awareness about the organic basis of post-concussional syndromes, it's likely that for many of these persons better and more appropriate treatment can be offered.

Adapted from "Head Injury Symptoms: Brain vs. Neurosis", Charles Furst, Ph.D., Los Angeles Trial Lawyers Association.

Head Injury and Traumatic Brain Injury (TBI)

There are numerous types of traumatic brain injuries, among which are concussion, brain stem injury, closed head injury, cerebral hemorrhage, depressed skull fracture meningitis (from a fracture that exposes brain to germs), open head injury (foreign objects), anoxia, aneurysm, and stroke.

Head injury can happen to anyone anytime, and while no one is immune, statistics show that twice as many males are injured as females and that males sixteen to twenty-four years of age incurred more head injuries than any other group. Half of all head injuries are caused by motor vehicle accidents. Other causes of head injuries are falls, sports injuries, near drownings, industrial accidents, assault, and gun shot wounds.

According to the National Head Injury Foundation, two million head injuries occur each year in the United States. Of this group:

- 70,000–100,000 persons die as a result of a head injury.
- 500,000 persons require hospitalization as a result of a head injury.
- 70,000–90,000 suffer life-long physical, intellectual, and psychological disabilities as a result of a head injury.

This estimate includes head injuries categorized from mild to severe. Although exact data detailing the morbidity and modality from traumatic head injury in this country are unavailable, a num-

ber of studies have allowed estimates to be made which document the seriousness of the problem.

Serious head injuries usually result in prolonged loss of consciousness or coma which may be brief, lasting only a few minutes, or may extend to days or weeks. If the period of coma is brief, recovery to full or nearly full function is likely; but as time in coma lengthens, emergence to a fully alert state can take a long time. Intellectual impairment, speech problems, behavioral disorders and other related physical disabilities can become realities. The individual and his or her family face a lengthy period of rehabilitation that can extend for years. Most head injuries result from accidents, but similar problems can result from conditions such as encephalitis, lack of oxygen to the brain, and cerebral hemorrhage.

Typical Impairments of Individuals with Head Injury

The typical impairments you may encounter in individuals with head injury fall into three broad categories: physical, cognitive, and psycho-social-behavioral-emotional impairments. Any or all of these impairments may occur in varying degrees. A severely impaired individual's impairments may encompass all of the below, but it's important to note that with early and ongoing therapeutic intervention, the severity of some of these symptoms might decrease. Intellectual ability might not improve, but social and behavioral aspects and memory could improve over long periods of time.

Types of physical impairments may be:

- Aphasia
- Hearing
- Hemiparesis
- Paraplegia
- Physical disability; orthopedic involvement
- Seizures
- Spasticity
- Visual impairment

Types of cognitive impairments may be:

- Attention
- Concentration
- Headaches
- Judgment
- Lack of foresight
- Memory deficit (short & long-term)
- Perception
- Planning (sequencing difficulty)

Psycho-social-behavioral-emotional impairments may include:

- Agitation
- Anxiety
- Denial
- Depression
- Disinhibition
- Egocentricity
- Emotional lability
- Euphoria
- Fatigability
- Inability to cope
- Lack of motivation (inability to self-monitor)
- Lack of self-esteem
- Restlessness
- Sexual dysfunction

Factors Affecting the Outcome of Head Injury

- Age at the time of the brain injury
- Location of the areas of the brain dysfunction
- Severity of the brain damage and the length of coma
- Time lapsed since the injury occurred
- Preexisting intellectual skills
- Preexisting personality characteristics
- Type of environment since the injury
- Motivation for recovery
- Nature of the family constellation and involvement
- Rapid entry into a rehabilitation facility with programs for the rehabilitation of the head injured.

Treatment

Once the patient is out of coma, both he or she and the family must look forward to a long period of rehabilitation. Substantial gains can be expected over the first year, and additional improvements will occur for at least two to three years. Even those injured many years previously can make gains when placed in the proper therapeutic setting.

Predicting long-term outcome and degree of disability after serious head injury is much more difficult. It's true that the longer coma lasts, the greater the disability is likely to be. For all individuals surviving six hours or more of coma, over half will return to school, jobs, or independent living by a year after injury, although many will have some residual cognitive problems. Those coming

out of coma in the first day or two will do better than those remaining in coma a longer period of time, but one cannot predict with certainty what will happen in each individual case.

A great variety of rehabilitation and services are needed by individuals with brain injuries. New techniques of cognitive remediation, behavior modifications, and memory retraining are needed to advance the head injured individual from coma to community. They require opportunities like family counseling and support; legal and financial counseling; long-term rehabilitation centers; vocational training and day programs; community residences and transitional living; and educational opportunities. Examples of resources include the Minnesota Head Injury Association and the Department of Human Services.

Why This Information is Important for the Health Paraprofessional

Many individuals in high school, post-secondary education, and in employment have had accidents, injuries, or illnesses resulting in brain injury. Depending on the involvement, the individual may need support for feeding, toileting, accommodations, medications, or in case of seizure activity. It's important to know the characteristics and challenges that face these individuals so you can begin to understand and recognize behaviors that may be a result of the brain injury and those that may be personality traits. This can help you in helping the individuals through the frustrations and difficulties that often accompany the adjustment of individuals to their own (new) limitations as a result of the brain injury.

Section 15

Primary Immune Deficiency

When a defect in the immune system is inherited (carried through the genes), it's called a *primary immune deficiency*. More than seventy primary immune deficiency diseases, ranging widely in severity, have been identified to date. Among these seventy-plus primary immune deficiency diseases are IgA deficiency, hypogammaglobulinemia – also called *common variable immune deficiency* (CVI) – IgG subclass deficiency, compliment deficiency, chronic granulomatous disease (CGD), X-linked agammaglobulinemia (XLA), and severe combined immunodeficiency (SCID), in which the body has virtually no immune defenses.

Primary immune deficiency affects as many as one person in five hundred and can strike males and females of all ages, though they frequently occur early in life. The more severe immunodeficiency diseases are detected most frequently in children.

It's important to remember that even though both involve the immune system, primary immune deficiency and acquired immune deficiency syndrome (AIDS) are very different and should not be confused with each other. Primary immune deficiency is inherited; AIDS, on the other hand, is acquired by contracting the HIV virus. The HIV virus is sometimes passed from a mother to her unborn child, but this is still an infectious, rather than a genetic, problem.

Though it's hoped that research efforts in primary immune deficiency and AIDS will at times benefit each other, they are still completely separate conditions where diagnosis and treatment are concerned.

Symptoms

Primary immune deficiency diseases don't have unique symptoms of their own. Rather, they appear as "ordinary" infections, often of the sinuses, ears, or lungs. These infections can be chronic – which means they keep coming back, sometimes frequently, and can be severe. They also tend to require prolonged recovery, and may respond poorly to a conventional course of antibiotics. They can also cause gastrointestinal problems or inflammation of the joints.

People with primary immune deficiency can have long periods of normal health, then suddenly be struck by high fevers, pneumonia, or any of the other problems noted below. The illnesses themselves are frightening, the lack of a definite diagnosis and treatment is frustrating, and "waiting for the next attack" can turn even the healthy periods into times of great anxiety.

Primary immune deficiency can result in:

- Infections of the type noted above, leading to frequent bouts of sinusitis, bronchitis, and pneumonia
- Thrush in the mouth after the first year of life
- Recurrent abscesses
- Meningitis
- Osteomyelitis
- Cellulitis

All these problems could have a number of causes, but when they occur the possibility that primary immune deficiency is present should be explored. Early diagnosis and treatment of primary immune deficiency disease is essential to prevent recurring infections from doing permanent damage. Unfortunately, the lack of unique symptoms causes these diseases to resemble a great number of other illnesses. Thus, families and doctors are often unaware that the troubling conditions they are dealing with are actually rooted in a defect of the immune system.

Diagnosis

Correct diagnosis begins with awareness of the signs discussed above. Once the condition is suspected, doctors can order blood tests and screenings to evaluate the function of the infection-fighting cells of the immune system. Because primary immune deficiency is genetic in nature, blood relations of patients are often examined. Sometimes an unborn fetus can be tested for a specific disease. Of course, tests should be ordered as soon as primary immune deficiency is suspected, so that treatment may begin quickly if a problem is present.

Treatment

Once a diagnosis is established, much can be done for people with immunodeficiencies. At a minimum, the recurring infections can be treated with low or moderate doses of appropriate antibiotics. These can help prevent permanent damage to the lungs and bronchial tubes, thus promoting the individual's long-term survival while improving the quality of life.

A more basic therapy is to supply, when appropriate, the gammaglobulin that in some diseases the body can not make on its own. Such immunoglobulin therapy is now accepted for a range of primary immune deficiency diseases.

Other new therapies include advanced pharmaceuticals such as the interleukins, PEG-ADA, and gamma interferon. Bone marrow transplants can help in some cases.

Adapted from materials from the Jeffrey Modell Foundation, Department A: New York, NY.

Why This Information is Important for the Health Paraprofessional

Because of the increase in this condition, it's important for paraprofessionals to know about the characteristics in case you may be called upon to support some of the individual needs that an individual may require. What would the SHP need to know when caring for someone with either acquired or genetic primary immune deficiency?

Section 16

Spina Bifida

Spina Bifida means *cleft spine*, which is an incomplete closure in the spinal column. In general, the three types of spina bifida – in increasing severity – are:

- **Spina Bifida Occulta:** One or more of the vertebræ (bones) of the spinal column has an opening without apparent damage to the spinal cord.
- **Meningocele:** The meninges, or protective covering around the spinal cord, has pushed out through the opening in the vertebræ in a sac called the “meningocele.” However, the spinal cord remains intact. This form can be repaired with little or no damage to the nerve pathways.
- **Myelomeningocele:** This is the most severe form of spina bifida, in which a portion of the spinal cord itself protrudes through the back. In some cases, sacs are covered with skin; in other, tissue and nerves are exposed. Generally, people use the terms *spina bifida* and *myelomeningocele* interchangeably.

Approximately forty percent of all Americans may have spina bifida occulta, but because they experience little or no symptoms, very few of them ever know that they have it. The other two types of spina bifida, meningocele and myelomeningocele, are known collectively as *spina bifida manifesta*, and occur in approximately one out of every thousand births. Of these infants born with spina bifida manifesta, about four percent have the meningocele form, while ninety-six percent have myelomeningocele form.

Symptoms

The effects of myelomeningocele, the most serious form of spina bifida, may include muscle weakness or paralysis below the area of the spine where the incomplete closure (or cleft) occurs, loss of sensation below the cleft, and loss of bowel and bladder control. In addition, fluid may build up and cause an accumulation of fluid in the brain (a condition known as hydrocephalus). A large percentage (seventy to ninety percent) of children born with myelomeningocele have hydrocephalus. Hydrocephalus is controlled by a surgical procedure called “shunting,” which relieves the fluid build-up in the brain. Hydrocephalus may occur without spina bifida, but the two conditions often occur together. If a drain (shunt) is not implanted, the pressure buildup can cause brain damage, seizures, or blindness.

Educational Implications

Although spina bifida is relatively common, until recently most children born with a myelomeningocele died shortly after birth. Now that surgery to drain spinal fluid and protect children against hydrocephalus can be performed in the first forty-eight hours of life, children with myelomeningocele are much more likely to live. Quite often, however, they must have a series of operations throughout their childhood. School programs should be flexible to accommodate these special needs.

Many children with myelomeningocele need training to learn to manage their bowel and bladder functions. Some require catheterization – the insertion of a tube to permit passage of urine. The courts have held that clean, intermittent catheterization is necessary to help the child benefit from and have access to special education and related services. Many children learn to catheterize themselves at a very early age. A successful bladder management program can be incorporated into the regular school day.

In some cases, children with spina bifida who also have a history of hydrocephalus experience learning problems. They may have difficulty with paying attention, expressing or understanding language, and grasping reading and math. Early intervention with children who experience learning problems can help considerably to prepare them for school.

Inclusion of a child with spina bifida into a school attended with non-disabled young people, sometimes requires changes in school equipment or the curriculum. Although student placement should be in the least restrictive environment, the day-to-day school pattern also should be as "normal" as possible. In adapting the school setting for the individual with spina bifida, architectural factors should be considered. Section 504 of the Rehabilitation Act of 1973 requires that programs receiving federal funds make their facilities accessible. This can occur through structural changes (for example, adding elevators or ramps) or through schedule or location changes (for example, offering a course on the ground floor).

Children with myelomeningocele need to learn mobility skills, and often require the aid of crutches, braces, or wheelchairs. It's important that all members of the school team and the parents understand the child's physical capabilities and limitations. Physical disabilities like spina bifida can have profound effects on a child's emotional and social development. To promote personal growth, families and teachers should encourage children, within the limits of safety and health, to be independent and to participate in activities with their non-disabled classmates.

Information provided by the National Information Center for Children and Youth with Disabilities, Washington, DC.

Treatment

The advent of the ventricular-atrial shunt and the spitz-Holter valve in the 1950s, as well as other recent medical developments, have improved the overall survival rate and increased the life expectancy of children with spina bifida. Today approximately eighty-five to ninety percent of newborns with spina bifida can expect to survive. As a result, today's health practitioners are becoming more and more aware of the need to develop treatment plans that encompass not only the child but also the adult with spina bifida. Additionally, a more holistic approach to health care is called for in order to treat what often become secondary physically or psycho-sociological disabilities.

The shunt procedures provided the first effective method of managing hydrocephalus. By the mid 1960s, this form of treatment became more common, as did the Sheffield Policy of early spinal closure, which was developed by Dr. Sharrard and his associates in Sheffield, England. The results, however, were universally encouraging. In 1971, a study of babies born with spina bifida treated at the Sheffield clinic showed that only forty percent had survived at least seven years and many of the survivors were severely handicapped.

For many physicians and researchers, these results stimulated increased attention and innovation in the management of spina bifida. Today, aggressive treatment policies continue. These treatment policies are supported in many different regions by multidisciplinary teams to monitor the urological, developmental, and psychological needs of the individual in addition to the neurosurgical and orthopedic needs which have long been recognized.

Information from the Spina Bifida Association of America, Washington, DC.

Emerging Issues in Spina Bifida: Secondary Disabilities

Special attention is needed in the identification and treatment of secondary disabilities in the adult population. The wide range of neurological damage and mobility impairment in the current generation makes it sometimes difficult to identify some of these secondary disabilities. Despite this difficulty in identifying secondary disabilities, the occurrence of problems such as tendonitis in the upper arms, due to wheelchair use, is quite common. As services for adults with spina bifida are developed, it will become easier to develop a tracking system that will further define these secondary disabilities. Consequently, treatment programs and methodology will become more sophisticated and accurate in providing these services.

More attention must be focused on the psychological and so-

cial development of young adults with spina bifida, if they are to become empowered as adults who can function independently within their non-disabled communities. Many recent studies, including the Spina Bifida Association of America's Adult Network Survey, clearly indicate the presence of emotional problems resulting from factors such as low self-esteem and lack of social skills training. The key factor in addressing this issue is of emotional problems in the teaching of the skills needed in adulthood to these young adults at an earlier age.

Recent findings indicate that mental health service needs of individuals with disabilities can be divided into six major problem areas: social/interpersonal, self; vocational/career, personal/emotional; marital/family, and sexual. These needs may be translated into such service provisions as peer counseling, rehabilitation counseling, respite care, individual therapy, family therapy, and social skills training. These service provisions may be used in the effort to build necessary skills to maximum independence.

Adapted from materials prepared by the Spina Bifida Association of America, Washington, DC.

Why This Information is Important for the Health Paraprofessional

The health paraprofessional may be called upon to help with special health needs of the individual with spina bifida. You may also be called upon to help train the individual in self-care. Additional support may be needed if the individual also has shunts and bowel care may also require your guidance. Be sure you get the background information on the individual and learn the best ways to handle the needs of the individual that are consistent with their personal care routine at home.

Section 17

Teenage Suicide and Depression

Many who live or work with teenagers have had contact with a child who has thought of suicide. Studies show that seven out of ten teens have thought of killing themselves. Suicide is the third leading cause of death among young people. Accidents are the leading cause but some of these "accidents" may be suicides. An estimated two million teenagers attempt to take their lives each year and about 6,000 succeed. The suicide rates for teens has tripled since 1950. Minnesota has a higher than average suicide rate.

Adolescence is a difficult time for teens and their families. It's pretty normal to have a lot of ups and downs, or changes in behavior and personality which makes telling that a teen is having serious problems difficult.

Causes

There's no one cause associated with youth suicides. Researchers feel that stress, primarily due to multiple losses or changes, builds up for a teen and creates feelings of hopelessness, helplessness, and worthlessness which become depression. Some of the most stressful situations are:

- Unrealistic self-expectations.
- Breaking up with a boy- or girlfriend.
- Changes in financial or marital status of parents.
- Trouble with teachers and/or grades.
- Moving to a new home or school.
- Experiencing some social embarrassment.

Other contributing factors may be:

- **Social Expectations:** Teens are very impressionable and suggestible, they may be influenced to think of suicide as a solution to their problems after being exposed to the suicide of a friend or relative, movies, or media coverage of suicides.
- **Isolation:** Many teens don't have adults around with whom they can communicate about their problems. Both parents often work or children live in single parent families, teachers aren't as available, even the church is not as involved in a family's life as in the past.
- **Feelings of Failure:** Children are expected to be self-sufficient and successful at an early age. Parents, teachers, and children themselves may have unrealistic expectations for their performance. Many are unable to deal with any failure. Teens are very *now* oriented. We live in a fast-paced world, and teens want solutions and changes right now, and don't have the life experience to realize that things can get better with time.
- **Increased Alcohol and Drug Abuse:** Children who are in emotional pain may self-medicate to end those feelings. This just lowers inhibitions, clouds the thinking and increases the chance of a successful suicide.
- **Sexual Orientation:** Gay and lesbian teens are often forced to be secretive about their sexual preferences. As a result, they often feel "different" and alone. Without resources to talk about these feelings, they are at an increased risk for attempting suicide.

Depression

Depression is a common emotional disorder that until ten years ago was thought to affect adults only. As many as six million adolescents and children suffer from major depression – much of it unrecognized. Many harmful behaviors linked to depression are attempts by an individual to deal with the psychological pain. These may be drug abuse, eating disorders, truancy, delinquency or suicide. Depression can be a fatal disease: between 1960 and 1980, the suicide rate for the population between fifteen and nineteen years of age increased by 136 percent.

Depression can be the result of several things, the most common of which is stress. Kids these days are under a lot of stress, and usually there are multiple stresses occurring at the same time. Other causes of depression can include a genetic predisposition or family history of mental illness, especially depression or alcoholism, or a physical or chemical imbalance in the person's body.

Each person's reaction to stress is very individual. Some can tolerate more stress than others and for a longer period of time. When kids feel stressed it's their body's way of telling them that something is going on and that they have to take care of themselves. Getting more exercise and rest, maintaining good nutrition, or talking to friends about what's happening (including an adult) are all good ways to help relieve these kinds of stress. If the stressors continue, it can develop into depression.

Symptoms of Depression

The two most important signs are that the individual feels sad, hopeless, worried, and irritable and lacks interest in activities such as sports, hobbies, family and friends, indicating a change in his or her normal routine.

Other signs are:

- Poor appetite and weight loss – or excessive eating and weight gain.
- Sleep disturbances: insomnia, early morning awakening or excessive sleeping.
- Unexpected outbursts of anger or crying.
- Loss of energy, persistent boredom, listlessness or fatigue.
- Diminished ability to concentrate, decline in quality of school work and grades.
- Agitation, or violent or rebellious behavior. The difference between "normal" adolescent rebellion and depression is based on the time, degree, and amount of deviation from the child's usual personality and behavior. The acting out behavior may be normal rebellion if the behavior is temporary – lasting from a day to a week or two – and if it's broken by periods of calm between outbursts. If the rebellion is consistent, in-

tense, protracted over a period of months, and drastic (i.e., out of character), the behavior may be a result of depression.

- Major personality change.
- Complaints about physical symptoms such as stomach ache or headache.
- Self-reproach or inappropriate guilt – child blames him- or herself for all that goes wrong.
- Inability to concentrate.
- Recurrent thoughts about death or any suicidal thoughts or behavior.
- Isolating from friends or family or not participating in usual activities that once were fun.
- Neglect of personal appearance.

Tips for Dealing with an Individual Who May Be Depressed

- **Be Informed:** It's important that you're aware of the signs and symptoms of stress and depression.
- **Talk:** Ask questions about what you're seeing. Convey a sense of support, understanding, and openness to talk about anything. Be aware that depressed individuals are often hypersensitive to criticism and very self-blaming.
- **Listen:** Kids often are experiencing so much pain that they can't talk about what's really bothering them. Listen with your eyes and ears. Kids will often deny there's anything wrong, but you can see that there is a problem.
- **Empathize:** Take a young person's problems seriously. We often tend to minimize their importance and view their problems through "adult eyes". We know that things will get better, but we've learned that through years of living. They don't have that skill yet.
- **Get Help:** Know what resources are available. If a child is showing signs of depression or has thoughts of suicide or harming themselves, don't leave the child alone; get immediate professional help.

If there isn't immediate danger, you can help by:

- Identifying the major problems.
- Examining possible solutions – concentrating on strengths and past problem-solving skills.
- Formulating a plan, setting it in action through small steps.
- Identifying other people the child may talk with.
- Getting the child future oriented – make some plans for the weekend or midweek fun activity.

The sooner depression is diagnosed the better the chances are it can be effectively treated. Severe depression doesn't go away quickly on its own, but given early and appropriate help depressed kids can live a normal and productive life.

Warning Signs of Suicidal Behavior

Verbal Warnings

These can be subtle or blatant and include talking about death, dying, or suicide, or saying statements such as:

- "I won't be a problem much longer"
- "It's no use to go on"
- "Everybody would be better off without me"
- "I think I'll just end it all."

Behavioral Warnings

Kids often can't communicate their pain, so it comes out in behaviors such as:

- Giving away cherished objects which may often have little monetary value.
- Composing suicide notes, writing about death.
- Sudden change to being cheerful after a depression – a person will often have made the decision to end their lives and now feel a sense of relief.
- Preoccupation with death or interest in guns or medications.
- Acting out or isolating.

If there isn't immediate danger, learn the resources available for crisis intervention or counseling – and get the person help.

Tips for Preventing Teen Suicides

- Let them know it's OK to feel depressed but not to contemplate suicide.
- Talk to them openly and honestly about what you're seeing, and listen to them with both your eyes and your ears.
- Agree to be there to help but never agree to keep a secret about what's going on.
- If the teen has a specific plan for self-harm and the means to carry it out, call the police. Don't leave the child alone.
- Realize that children *do* have problems and that some are killing themselves. Try to see the problem through their eyes rather than from an adult's perspective.
- Encourage teens to have at least three people they can talk to

about what bothers them and that one should be an adult.

- Help children to learn to accept failure; love and loving is not dependent on their success or good behavior.
- Be a role model for stress management.
- Don't make the means for suicide accessible. Don't keep loaded guns or lethal amounts of medications in your home.
- Know the resources available in your community before you need them and don't be ashamed or afraid to ask for help. Pride isn't more important than someone's life.

Adapted from facts sheets prepared by Fairview Riverside Mental Health Services, Minneapolis, MN.

Why This Information is Important for the Health Paraprofessional

The health office is where chronic complaints or issues are often seen. As the health paraprofessional, you need to be aware of the symptoms for teenage depression and suicide. What may seem like a nagging teenager to you may really be a teen reaching out for help. You may be the one individual the teen has approached. Record the times the individual comes to you and for what reason. Talk this over with the nurse. Make a recommendation if you feel there's something deeper going on. You may be the person who can save a teen's life. Do *not* underestimate your importance in this matter.

Case Study

Cory is a fifteen year old boy who drops in the health office with an array of slight ailments three or four times a week. There usually isn't anything you can do to help his physical condition (because he's pretty healthy) but you end up chatting with him. In the course of your conversations, you learn that Cory doesn't feel he's a very good student and that he has no real friends at school. He also tells you that home is a pretty sad place since his sister committed suicide two years ago (at the age of seventeen). You like Cory and feel concerned about him, but Cory has no real health care needs so you don't know what to do for him. Then suddenly, Cory stops coming to see you. What do you do? Should you express your concern to the LSN or other professionals in the building?

Section 18

Tourette Syndrome

Tourette Syndrome (TS) is a neurological multiple tic disorder which begins between the ages of two and sixteen and lasts throughout life. The symptoms of this developmental disability follow a waxing and waning course. TS isn't degenerative or fatal.

TS is caused by a chemical imbalance in the brain. The disorder appears to be genetic in about 85% of cases. In these families, one or more relatives have been identified with either milder tic conditions or Tourette Syndrome. This would indicate that mild tic conditions are probably a genetic continuum of one disorder, and TS is the most severe end of that spectrum.

A number of children have been identified with stimulant induced TS. Stimulant medications prescribed to hyperactive children (i.e., Ritalin, Cylert, Dexedrine, etc.), can sometimes precipitate TS in predisposed children according to the Food & Drug Administration (FDA).

Symptoms

Motor Symptoms

TS is characterized by multiple involuntary tic movements, the most common being rapid eye blinking, shoulder shrugging, facial twitches, head, arm or leg jerking. These repetitive muscular movements are commonly misinterpreted as "nervous habits" or a behavioral abnormality. TS tics and twitches always get worse under stress; they may lessen or disappear for short periods of time during non-anxious focused attention to a task or activity.

Vocal Symptoms

Motor symptoms are combined with uncontrollable vocalizations such as repeated throat clearing, grunting, sniffing or hissing. These symptoms can also be misinterpreted as a "nervous cough" or "bad habits." In more severe cases vocalizations can be quite loud and disturbing such as shrieking, barking, and/or abrupt outbursts of sounds or words. In thirty percent of cases people with TS will get coprolalia, which is involuntary outbursts of obscene words. Other speech problems can occur including echolalia (repeating the words of others), palilalia (repeating one's own words), stuttering, speaking in uneven rhythms, accenting syllables, etc.

Behavioral Symptoms

Behaviors commonly associated with TS may include attention deficit, hyperactivity, impulsivity, learning disabilities, imitating

movements and gestures of other people, and/or obsessive-compulsive or ritualistic behaviors. Compulsive behaviors may include touching or rubbing objects, checking repeatedly to see if doors are locked or if the stove is turned off, ripping, breaking or hitting objects, etc. In the most severe cases, self-mutilating symptoms may occur including head banging, biting, or hitting oneself. Examples of ritualistic behaviors may include compulsively walking through doorways with a specific foot first, jumping, hopping, touching the floor, having to arrange and rearrange objects in a specific manner, etc. These can be the most crippling behavioral symptoms of TS because they consume so much time.

Diagnosis

Many persons with TS are misdiagnosed for a lengthy period of time due to professional unfamiliarity with the syndrome. Commonly, families have brought children to a wide variety of professionals during their search for a diagnosis. Individuals may be told their symptoms are caused by psychological factors and will often be referred to mental health practitioners. They are often wrongly advised the symptoms are "nervous habits" which will disappear eventually, or they are misdiagnosed with a variety of ailments. As a result, some people with TS have been treated with ineffective and even dangerous therapies. The correct and/or confirming diagnosis and treatment plan should be made by a neurologist, psychiatrist, or neuropharmacologist familiar with diagnosis and treatment of Tourette Syndrome.

Treatments

The only proven effective treatments for Tourette Syndrome are pharmacological. Most often used medications include neuroleptics such as haloperidol (Haldol), pimozide (Orap), fluphenazine (Prolixin), clonidine (Catapres) which is an anti-hypertensive medication, and antidepressants for obsessive-compulsive symptoms such as clomipramine (Anafranil) and fluoxetine (Prozac). Information about each of these medications is available through the Tourette Syndrome Association. It's important to consider side effects of any therapeutic agent when dealing with a client who has TS. Some medications can cause severe depression, short-term memory problems, cognitive interferences, etc. Psychotherapy is not an effective treatment for the symptoms of TS. However, it can be very helpful in assisting TS clients to adjust to, understand, and cope with the effects of Tourette Syndrome. The need for assistance with this adjustment cannot be minimized.

Implications

The motor, vocal, and behavioral symptoms of TS can be quite disturbing to the person with TS, his or her family, and society in general. TS symptoms are often perceived as bizarre and frightening. The years during which a client is undiagnosed or misdiagnosed can have a lasting psychological impact. The client may have been punished by family, rejected by teachers, teased by peers and looked upon as a disruptive or emotionally disturbed child. Children with TS shouldn't be placed in time-out or in E/BD programs.

It isn't surprising that the undiagnosed person with TS often begins to question his or her own sanity. However, studies have shown that the severity of motor and vocal symptoms aren't the predictors of satisfactory or unsatisfactory adjustment. Rather, the behavioral disabilities, degree of family support, effectiveness of medication, educational level, intelligence, etc., can help or hinder a person's later independence and productivity. Some people with very severe motor and vocal symptoms have succeeded in all areas of life and even pursued professional careers which exceed the goals of people without disabilities. Others, with only minor motor and vocal symptoms, can be severely disabled by their behavioral symptoms and/or emotional maladjustment. There's no set formula which draws a line between the difficulties a person with TS faces in his lifetime as a result of having the disorder, the implications of misdiagnosis, and those behaviors which are a part of the syndrome itself. "Where does the Tourette Syndrome end and the person begin?", is a question often asked by service providers who are working with a person with TS. Like most neurological impairments, this answer is not yet clear.

Important Characteristics

People with TS can postpone or substitute symptoms for a variable period of time. Implications of this characteristic may be both positive and negative:

- People with TS tend to hold back their symptoms when in the presence of strangers. Thus, one reason TS is often misdiagnosed is because the person may not display symptoms in the doctor's office. It's important that the diagnosing physician schedule a lengthy initial office visit. If symptoms don't appear after some time, persons with TS should be asked to sit in a place where they're unaware of being observed (i.e., a waiting room). At that time the symptoms will probably be expressed.
- A great deal of energy and concentration must be used to hold symptoms back while they're being postponed. At those times, the client is usually not listening to speakers, teachers, etc., and performance can be impaired. In a learning situation, it's bet-

ter to allow symptoms to be expressed.

- Symptoms will be expressed more explosively after they've been held back. Therefore, persons with TS should be given a "safe place" to go where they may release their symptoms without disturbing others. In school this can be an empty classroom, nurse's office, etc. At a place of employment, a nearby restroom or an office providing privacy might be used.
- The great majority of people with TS can drive cars and work with various equipment. They don't lose consciousness during their tics. Since they can postpone or substitute symptoms for varying periods of time (according to the severity of the case), they are usually able to do precise work without their motor movements interfering. As soon as a task is finished, they may have to express more intense repetitive movements in order to compensate for the postponement of motor activity. Therefore, they may require extra time to complete a task.
- The compulsive component of TS can some times work to the person's advantage. Many people with TS feel that they must do things perfectly. As a result they can be excellent workers because they will settle for nothing less than a job well done. This characteristic, if it doesn't become too time consuming or ritualistic, can be one of the client's greatest assets.
- People with TS have the same range of intelligence characteristic of the general population. A few cases of mentally retarded people with TS have been reported, while the remainder have average to above-average intelligence.

Educational Implications

The educational implications of TS are complicated because of the variable degree of social factors, learning disabilities, cognitive impairments caused by medications (or occurring naturally), teacher unwillingness to accept TS symptoms, the degree of motor and vocal control, and the effects of psychological stress. Tourette Syndrome is a handicapping condition under Federal Law – the "Education for All Handicapped Children Act" (PL 94-142) now updated as IDEA. Children with this neurological impairment are eligible for special education and related services. Sixty percent of children with TS have identifiable learning disabilities which can intensify their difficulties in the classroom.

Learning disabilities associated with TS often involve mathematics and/or certain areas involving language. Sometimes math problems actually involve handwriting difficulties such as not writing numbers in the correct column, placing decimal points in the incorrect place, etc. Language difficulties can involve both the understanding of language and language production. These difficulties usually don't become apparent until the upper grades when the child is expected to comprehend more complicated vo-

cabulary and sentences.

The most common problem faced by students with TS involves their basic responsibility to sit still, pay attention and be quiet. Because they aren't always capable of doing this they must be allowed some freedom of movement and not be reprimanded for being fidgety, taking too many trips to the lavatory, etc. Attention Deficit Disorder (ADD) is a common component of TS, and the student may often need to be guided back to the task by teachers.

Another common problem involves handwriting difficulties. Handwriting may be sloppy or illegible. People with TS may have great difficulty forming letters, they may compulsively tear paper, put dots in places where they don't belong, or go over and over letters. In those cases where handwriting doesn't appear to be sloppy, we often hear that the "perfectionist" compulsive behaviors which make the child write neatly (and if it's not neat enough, the child will do it over and over again) take extensive periods of time. Children with TS generally find it difficult to copy notes from a blackboard and may require hand written notes on a piece of paper so that they don't have to focus from a near to far distance repeatedly.

The writing problem is also impacted by the psychological effects of stress. Stress always makes tics worse, and time limits are a common source of stress to students with TS. In these cases tests should be given without time limits, and sometimes in a separate quiet room. At times substitutes for writing must be offered; the child can be given a tape recorder or allowed to dictate answers to another person; written notes can be given to the student by a classmate who has used carbon paper while taking notes.

Behaviors can also cause educational problems. The child may be perceived as hyperactive and/or a discipline problem because he or she disturbs peers, calls out in class, touches other people, etc. These behaviors do indeed represent a problem for a classroom teacher. However, proper diagnosis, medication (when indicated), appropriate adjustment to the child's program and/or psychotherapy might be appropriate interventions according to the individual circumstances.

Adapted from materials prepared by the Department of Family & Professional Services, Tourette Syndrome Association, Bayside, NY.

Why This Information is Important for the Health Paraprofessional

The health paraprofessional needs to be aware of these symptoms and may be called upon to help in the classroom or on the job with the individual or offer a quiet place for the individual to go to when needed. Most often with the individual with TS, the paraprofessional may also be delegated to dispense prescribed medications during the day.

Section 19

Tuberculosis

Tuberculosis (TB) is a contagious disease that primarily affects the lungs. Until recently, tuberculosis had become a nearly forgotten disease in the United States. Once treated in remote fresh air sanitariums, the public no longer considered this contagious disease a significant threat to their health. Improvements in drug therapy, nutrition, hygiene, and hospital care in the 1950s had kept TB in steady decline until 1986. Today, an estimated ten to fifteen million Americans are infected with TB and over 20,000 new cases are reported annually. The most notable increases in infection rates have occurred in groups and in areas with a high prevalence of AIDS or HIV infection. According to the Center for Disease Control (CDC), the incidence of TB in persons with HIV infection is almost 500 times greater than in general. Additionally, new drug-resistant strains of the disease have recently been reported.

There are two very frightening facts about TB. First, anyone can get it: nothing more than breathing is required for transmission to occur. Second, despite the fact that TB is preventable, easily detected, and is today a largely curable disease, five percent of all cases are first reported at death.

Transmission

TB is spread by airborne bacteria produced by a person with untreated TB of the lungs or larynx when she or he coughs, sneezes, speaks, or sings. Another person who repeatedly inhales air contaminated with the bacteria may become infected. Persons at highest risk of being infected are close contacts, such as those living or working with an infectious person. The duration of exposure required to transmit TB is highly variable and depends on the infectiousness of the source case. Many studies seem to indicate that TB is more infectious in persons with HIV.

Inhaled particles containing the TB bacteria are usually trapped in the protective lining of the respiratory tract and are expelled. When this happens, no infection occurs. However, tiny particles may be inhaled beyond the clearance mechanisms and may be carried to the air sacs of the lungs where they can establish an infection. In most persons with a healthy immune system, the infection is contained and active tuberculosis doesn't develop. Even so, a healthy immune system often doesn't destroy all of the bacteria and small numbers of dormant organisms remain in the body. Some infection may be carried by the lymph system or the bloodstream to distant tissues and organs. With dormant organisms in the body, a person remains at risk of developing active TB. Unless preventive measures are taken to eliminate these dormant

organisms, the germs may overcome the body's defenses at any time and begin to multiply; active disease will then develop.

Although the lung is the most common site, TB may also affect other tissues or organs in the body such as the lymph system, the gastrointestinal system, the brain, or the joints. Only persons with pulmonary TB (TB of the lungs or larynx) are contagious to others: because TB is spread by airborne droplets, TB contained in other tissue or organs is not contagious.

TB Infection vs. TB Disease

TB infection is not the same as TB disease. A person infected with TB has the potential to develop the disease at any time but doesn't have the disease. TB infection is diagnosed by a skin test while TB disease is diagnosed by evidence of organ damage and cultures (tests that show the organism).

Persons who are infected but don't have clinically active pulmonary TB are not infectious. Once infected, a healthy person will give a positive reaction to a skin test that gauges whether or not their immune system recognizes the protein from the TB bacterium. This is known as an *asymptomatic primary TB infection* because the infection is associated with a positive skin test but occurs in the absence of signs of the disease.

Unfortunately, the symptoms of TB disease are vague and vary with the location of the infection. Symptoms of pulmonary TB include a moist cough lasting more than three weeks, chest pain, or coughing up blood. Symptoms typical of active TB anywhere in the body include fevers, chills, weight loss, loss of appetite, fatigue, nausea, night sweats, and weakness. If symptoms are present despite a negative skin test, further diagnostic studies should be done to rule out TB. As TB is a slow growing organism, bacterial cultures may take as long as twelve weeks to grow, although a bacterial smear may give earlier information as to the type of bacteria present.

Diagnosis

The Mantoux TB skin test (purified protein derivative or PPD) is recommended for accurate diagnosis. This test involves using a small needle to inject tiny amounts of purified tuberculin protein into the upper layers of the skin, usually on the inside of the forearm. The skin test gauges the immune system's familiarity with TB. If the immune system recognizes the skin test protein as one it has dealt with before, the injection site will become reddened and swollen (indurated). The test is read in 48-72 hours by measuring the size of the induration.

Because of damaged immune systems, HIV infected persons may not be able to generate the immune response necessary to react to a TB skin test. A smaller amount of induration is then in-

terpreted as a positive skin test in persons who are HIV positive. A positive skin test indicates that an individual has been exposed and is infected. Further diagnostic studies are required to diagnose TB disease.

Many HIV infected persons may not be able to react to the tuberculin protein at all because of damage done to their immune system by HIV. This is known as *anergy*. Anergy testing, done to determine whether or not an immune response can be generated, should be performed along with the Mantoux TB skin test.

Anergy testing involves the injection of tiny amounts of proteins to which most people have been exposed, usually mumps, candida or tetanus toxoid, into the upper layers of the skin and watching for a response. If a person doesn't respond to these very common proteins, it's likely that he or she would also not be able to respond to the TB protein. A negative TB skin test along with a negative anergy test, then, doesn't assure us the person is free of TB infection.

Treatment

Early diagnosis and treatment is the key to limiting the spread of TB. In most cases, appropriate antibiotic therapy quickly eliminates a large number of infectious organisms and after a few weeks of treatment a person is no longer infectious. Most persons infected with TB should receive preventive drug therapy so that they don't go on to develop TB disease. The risk of an otherwise healthy infected person with TB infection developing active TB is about ten percent during their life time. Nine of ten persons would not ever develop TB even without preventive therapy.

The goal of preventive therapy is to prevent TB infection from developing into active TB. Current preventive therapy involves six to twelve months of Isoniazid taken daily. The CDC currently recommends a twelve month course for HIV positive persons. Twelve months of therapy will reduce the risk of tuberculosis by over ninety percent.

Some clinicians recommend preventive therapy in anergic HIV infected persons who are at risk of contracting TB. Standard antituberculous drugs are not, however, without risks. Ten to twenty percent of patients receiving standard therapy develop liver toxicity. As most men with hemophilia already have some degree of liver disease, the benefits of prophylactic therapy must be carefully weighed.

There are a variety of drugs available for treatment of TB disease. Treatment should involve the use of at least two – preferably three – drugs in combination to help prevent the emergence of resistant organisms.

The goal of all treatment is to provide the most effective therapy in the shortest time; however, adequate treatment of TB involves long-term drug therapy. While most persons with hemo-

philia have grown to accept long-term drug therapy as a necessary part of life, many others have not. It's often very difficult for people to take medications on a long-term basis, especially when they're feeling well. Antituberculous drugs eliminate most susceptible germs quickly and relieve bothersome symptoms, but the strong, obstinate organisms that may remain can mutate and become resistant to standard TB therapy. Should these remaining resistant organisms again become active, the resulting disease will be more difficult to treat and the infected person will be capable of transmitting the drug-resistant disease.

As previously noted, strains of TB that are resistant to many antituberculous drugs have been reported around the world. In the United States, approximately seven to ten percent of reported cases involve drug-resistant organisms. Primary resistance occurs when a person is infected with an organism that is already resistant. Secondary resistance occurs when the organisms become resistant during the course of therapy. The occurrence of primary antituberculous drug resistance is an indicator of transmission of a resistant organism from patients who have received inadequate or inappropriate treatment.

Treatment of drug-resistant TB is very difficult. Additional drugs are usually added to the standard regimen in hopes that the organisms will not be resistant to them. Recently, strains of TB bacteria have been isolated which are resistant to all of the first-line, most effective drugs and successful treatment has been very difficult.

Information taken from the Hemophilia Update, First Quarter, 1993, Number 30, Hemophilia Foundation of Michigan, a United Way Agency.

Why This Information is Important for the Health Paraprofessional

Because TB is on the rise – and many people aren't aware that it is – they may not detect the symptoms in an individual they work with. You must know these symptoms so you can, if needed, refer an individual for further help and treatment. By being able to describe these symptoms to others who may work with students in the classroom, you may help them in discovering TB early and helping the individual in the early stages of infection.

Summary

Individuals may have any number of many disabilities. The disabilities included in this chapter were identified by LSNs as those they see most frequently in the school setting. It's important for SHPs to be aware of basic information about disabilities so they

will be familiar with these conditions. Understanding a specific disability can provide the SHP with greater empathy and greater awareness to meet as individual's needs.

Questions to Ponder

- When working with any person with a disability, what are common issues the individual must face?
- What's your role in working with individuals with disabilities?
- How can you assist individuals with disabilities to meet their basic needs?

9

Chapter Nine

Selected Health Procedures: Specific Instructions

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Introduction

This chapter is designed to give health paraprofessionals some specific direction in terms of selected health care they may be asked by the LSN to perform on the job on a regular basis. The following areas have been chosen because they are the most common situations found by health paraprofessionals.

Many of the sections in this chapter are broken into four parts: *Definition, Equipment Needed, Student Considerations and Accommodations, and What to Ask*. The sub-sections are designed to give you the information in as simple and as useful a manner as possible.

This chapter discusses some selected health procedures from a general description only. These are conditions aren't described in detail because, while you might be exposed to them, you must first have specific training beyond the scope of this module to work closely with each of these conditions. The LSN will usually provide the SHP with specific training, demonstrations, and supervision.

Section 1

Assisted Eating

You may be working in a setting where individuals need help eating. There may be classroom paraprofessionals who handles most of this support or you may also be called upon to offer assistance.

Many individuals who need assistance eating will have specially designed or adapted equipment for this purpose. This equipment is usually designed or modified by an occupational therapist. Such equipment may include a spoon adapter or a spoon bent in such a way as to assist a particular individual's needs. Adaptations may also be a plate with built-up sides or a plate or bowl with a slip-proof bottom. Other adaptations may be more specialized.

The following are some tips to remember when assisting someone with a disability with eating:

- Make sure the student is seated properly – sitting up straight with feet on the floor.
- Sit at the student's eye level.
- Be careful to use the correct adapted equipment with the right student. Because it's specially designed for each person, you must make sure you have that person's equipment. All the dishes and adapted equipment are often kept together on a tray. Make sure it's marked or there's a chart so everyone knows what equipment belongs to whom.
- Be careful to give each individual the correct food and be careful not to feed the individual too much, or too much at one time.

- Offer the food separately rather than mixed together. Alternate types of food.
- Watch for individuals who may be “packing” food in their mouths but not really chewing and swallowing it. If the individual is packing food or ruminating, or chewing for a long time although you continue to give him or her food, there's a danger he or she might choke. Watch carefully.
- Students who have difficulty in swallowing need to have food cut into small pieces or foods with thicker consistencies (easier to swallow). The SHP should stay nearby to observe eating and needs to know proper first aid for choking.
- Give the individual the amount of time he or she needs to eat, but set a limit on the amount of time.
- Encourage the student to help him- or herself as much as possible.
- Provide a pleasant environment for the individual while eating. Play music, eat with the mainstream population, talk with the individual.
- Encourage the supervising teacher or licensed school nurse to keep a laminated index card containing current on each individual posted in a designated area. This card should list the adapted equipment the person needs for eating, dietary requirements, food allergies, and any other special instructions that people providing assistance in eating need to know about each student.

Section 2

Body Mechanics & Handling/Positioning

Walkers, wheelchairs, crutches, canes – all of these devices have one purpose: to aid mobility. This is a major concern for many individuals with a chronic health condition or disability that impairs mobility. A person's ability to move from one location to another is obviously crucial, not only for learning but for feeling “a part of the group.” You may be called on to help.

This raises a whole series of questions: What is the best way to transfer a person from a wheelchair to another surface, such as a chair or toilet? What individuals are good candidates for power wheelchairs? A person with no mobility may need lifting to be placed on a toilet seat; how do we do that without injuring the individual - or caregiver? How can we put the individual in a sitting or standing position so he or she can take part in the activity?

Individuals with physical limitations vary widely in mobility.

Some are totally dependent. These individuals, for example, may use a wheelchair; you would have to lift them when transferring them from a wheelchair to a toilet. In contrast, other individuals will never use a wheelchair. They will walk and transfer themselves independently, perhaps with the aid of an orthosis, a supportive device, or both. (Orthoses are appliances that provide support to a limb or joint).

You may become directly involved with an individual's transfers and any equipment needed for that purpose. Before you do, gather information about:

- Medical diagnosis, including special problems such as susceptibility to fractures.
- Equipment currently being used, such as wheelchairs, orthoses or walkers.
- General level of mobility.
- Any recent surgery that may affect handling techniques.

Levels of Mobility

Level I: Totally Dependent

Individuals at Level I may have voluntary head control, but require support to sit. They need to be totally lifted for transfers and are dependent for all care. Examples are individuals severely involved with cerebral palsy, individuals with a high level myelomeningocele (spina bifida) or spinal cord injury, or those in the advanced stages of Duchene's muscular dystrophy.

Your goal at this level is to safely transfer the individual and to promote self-care. Many individuals who need total lifting are severely spastic. For example, individual with cerebral palsy tend to hold their bodies in a totally extended position. In order to place them in the sitting position, it's best to bend them sharply at the hips. Hold them in this flexed position as you place their buttocks down and back and then secure any lap belt.

Safety Precautions: Because these individuals require extensive lifting, the greatest safety concern is that the caregivers not harm their backs by lifting too much weight. If you have any doubt, get help before starting to lift. Always have two people present if you're transferring an individual for the first time.

Making a Transfer: These are the steps you should take to safely transfer an individual at Level I.

- 1 Plan the transfer carefully. Place the individual as close as possible to the surface to be occupied. Make sure there are no obstacles and that the surface is stable.
- 2 Lock any wheels on the chair or buggy in which the individual is sitting. Do the same to any chair or buggy in which you're

- placing the individual.
- 3 Unfasten any straps or buckles.
 - 4 Bend your knees and keep Your back as straight as possible. Do the majority of the lifting with your legs, not your back.
 - 5 Reach behind the individual at the shoulders and under the buttocks. Support the head and legs with your arms.
 - 6 Keep the individual as close to your body as possible. Lift and come to a full standing position.
 - 7 Move to the new surface and lower the individual by bending your knees. Keep attending to the individual until the straps have been secured.
 - 8 Coordinate the moves of the people lifting with verbal cues.

A two-person transfer may be needed for lifting a larger individual, and the procedure is similar. There's a difference, however: one person lifts under the shoulders and low back. The second person lifts under the buttocks and knees.

Level II: The Individual in a Wheelchair Who Assists with Some Mobility

An individual in this category would be seated in a wheelchair most of the time. This individual, though probably unable to propel a manual wheelchair, could manage a powered chair. He or she could assist with self-feeding and dressing. Examples would be individuals with mild cerebral palsy or muscular dystrophy less advanced than Level I.

Your goal at this level is to safely transfer and assist the dependent individual, allowing him or her to help as much as possible.

Safety Precautions: This individual provides minimal help in transferring. Still, proper lifting techniques are essential to help caregivers avoid back strain. If you have any question about this, get more help before starting to lift.

Making a Transfer: These are the steps you should take to safely transfer an individual at Level II.

- 1 Plan carefully to minimize the distance the individual must be moved. It's best to move from one surface to another without taking any steps.
- 2 If possible. Ask the individual to do a standing pivot transfer. Start by locking the wheelchair in such a position that a quarter-turn will get the individual from one surface to the other. This works best when the individual is able to bear a little weight on his or her legs, and is not obese or excessively tall.
- 3 Unfasten any straps or buckles: face the individual. Put a transfer belt on him or her if necessary. Help the individual to slide

forward as much as possible.

- 4 Ask the individual to put his or her arms around your neck, if possible. Grip the safety belt behind the individual, or get the individual's buttocks. Bend at your knees, not your waist.
- 5 Agree on a pre-arranged signal. At the signal, the individual should try to stand as you lift by straightening your knees. When the individual is in full stance, he or she can be supported by leaning against your body. Come to a full stand before beginning to turn.
- 6 Pivot together. Help move the individual's feet with your own if necessary.
- 7 Slowly lower the individual onto the surface by bending your knees.
- 8 Adjust the individual's position in the new location, making sure that buttocks are well back. Attach any buckles or straps.

Level III: The Individual Who is Independent in Wheelchair Mobility

Individuals at this level are mobile in the community in a wheelchair. They can accomplish transfers essentially without assistance and are independent in feeding and dressing. Examples are the individual who has cerebral palsy that only minimally affects the arms and hands, or the person who is paraplegic from a spinal cord injury.

Your goal at this level is to monitor the progress of the individual in mobility and transfers. To help plan for any further steps in independence, stay aware of changes in the person's skill level.

Safety Precautions: Be aware of the individual's limitations to eliminate any possibility of injury.

Making a Transfer: These are the steps you should take to safely transfer a individual at Level III.

- 1 Accompany the individual to all places he or she would regularly go. Make sure that these facilities are accessible.
- 2 Observe the individual doing transfers and assess their safety.
- 3 Be aware of individual's speed and endurance. That way you can provide help for difficult terrain or long distances, if needed.
- 4 If possible. Ask the individual to do sliding transfers, side-to-side with the new surface to be occupied. These transfers can be done at an angle or by having the individual turn completely around. A sliding board may help. As an alternative, ask the individual to independently do a standing pivot transfer with grab bars. If you think complete independence is a possibility for the individual – even though it hasn't been achieved

yet – ask for consultation from therapists.

- 5 Make sure grab bars are accessible. This is essential when the individual is able to take a few steps – for example, from wheelchair to bathroom.
- 6 Check the condition of the wheelchair frequently. The individual's position in the wheelchair and mechanical maintenance of the wheelchair are significant for the individual at Level III. When needed, recommend changes or repairs.

Level IV: The Household Ambulator

Individuals at Level IV can move about home, school, and work on their own power, using some combination of prescribed assistive devices. These individuals might require extra time to get from place to place, but they need no help or supervision with toileting. When going long distances or on rough terrain, these individuals can use a wheelchair and self-propel it.

Such individuals would most likely have mild or moderate cerebral palsy. However, they might also have lumbar myelomeningocele (spina bifida) or one of the low incidence disabilities, such as dwarfism.

Your goal at this level is to monitor the safety and accessibility needs of an individual who primarily walks around.

Safety Precautions: Be aware of the individual's limitations to eliminate any possibility of injury.

Making a Transfer: These are the steps you should take to safely transfer an individual at Level IV.

- 1 Accompany the individual to all places he or she would regularly go. Make sure that all facilities are accessible.
- 2 Observe the individual in all areas to assess safety – especially on stairways and terrain that must be covered in bad weather.
- 3 Be aware of circumstances requiring the individual's speed or endurance. Determine whether or not the wheelchair is appropriate in such circumstances.
- 4 If the individual uses a walker. Make sure it provides the most support available. When using the walker, the individual should put it forward less than arm's length, then take a step with each foot. After stepping, the individual's body should still not be in contact with the front cross bar.
 - **Test for ideal walker height:** Ask the individual to stand erect, in line with the rear legs of the walker. The individual's elbows should be flexed about 30 degrees with hands on grips.
- 5 If the individual uses axillary crutches, make sure he or she uses proper technique. The individual can advance crutches simultaneously and then take a step with each foot or hop for-

ward. An alternate way is to advance one crutch and then step with the opposite foot.

- **Test for ideal crutch height:** A crutch is at an ideal height when the individual, standing erect, has two finger-breadths between armpit and top of crutch pad. The legs of the crutches should be several inches forward and to the side of toes. Elbows should be flexed about 30 degrees with hands on grips.
- 6 If the individual uses four-point canes, forearm crutches, or any other assistive devices. Make sure he or she uses the proper technique. The walking patterns can be similar to those above.
- 7 For some individuals, consider a less supportive device. This issue comes up when an individual is using an assistive device and appears to be totally safe and efficient, or uses it only partially. Individuals are never ready for a less supportive device until they are skilled with the one that offers more support for balance. The most support is provided by parallel bars. Next comes the walker, axillary crutches, forearm crutches, four-point canes and single point canes. Axillary crutches are most commonly used by persons with a cast or broken leg; they aren't usually meant for long-term use.
- 8 Make the change to a new assistive device in consultation with the individual's medical facility or a physical therapist. Direct treatment in therapy may be needed to make the transition.

Level V: The Community Ambulator

Individuals at Level V never use a wheelchair. They participate fully in all age-appropriate social activities. These individuals may use lower extremity orthoses or assistive devices. They need no help for self-care activities. However, they may need to make some adaptations to participate in sports. Examples of individuals at this level are those with mild cerebral palsy or with one or more limbs missing.

Your goal at Level V is to monitor the individual's progress in mobility. Keep track of changes in equipment or adaptations needed for mobility, sports or recreation.

Safety Precautions: Be aware of the environmental hazards such as uneven floors, dark corridors, loose stair treads, etc. These may interfere with safe mobility. Prevent disrepair or breakdown in assistive devices or orthoses.

Making a Transfer: These are the steps you should take to safely transfer an individual at Level V.

- 1 Accompany the individual to all places he or she would ordinarily go. Make sure that all facilities are accessible.
- 2 Observe the individual in all areas to assess safety – particularly on stairs, rough terrain and in crowded places.

- 3 Be aware of circumstances requiring speed or endurance from the individual. This helps determine if the individual needs to start early or be allowed to arrive late.
- 4 Be aware of changes in the individual's status – such as use of a walker, cane or other device – that may call for different accommodations.

Adapted from *Managing the Student with a Chronic Health Condition: a Practical Guide for School Personnel*, developed by Pathfinder and the School Nurse Organization of Minnesota, 1986.

Handling and Positioning

Handling refers to how an individual with a disability who needs to be moved is handled. There are specific ways that this should be done to both ensure the safety of the individual and the health of the one doing the moving. *Positioning* refers to how a person is put in position (a part of handling) to ensure his or her comfort and access to what is needed.

Equipment Needed

- Transfer belt (depending on the needs of the individuals)

Student Considerations and Accommodations

- Proper physical handling and positioning of individuals with disabilities who need assistance is basic care. Handling activities include lifting, carrying and transferring of individuals.

The use of correct handling techniques minimizes the risk of injury to students and to staff in performing these potentially physically stressful tasks.

Proper positioning ensures that individuals will be able to participate in activities as actively and comfortably as possible. Certain positions enable individuals to have better control of their body parts (e.g., head, arms, etc.). The goal of proper positioning is to provide adequate support and postural security (balance) for function and to prevent the development of abnormal motor patterns that can cause physical deformities. In addition to correct positioning, range of motion and relaxation exercises done on a consistent basis facilitates the individual's mobility and functioning in activities. Because teachers and assistants have primary responsibility for individuals during the school day, it's important that they be well-trained to handle, position and carry out needed exercises with correctly.

- Daily activities that require training for program assistants with respect to proper handling include the following:
 - Assisting students in getting on and off of school vehicles at arrival and dismissal times;

- Facilitating student mobility to and from the classroom and other school or community-based locations during the day;
- Positioning students for instructional activities with the aid of adaptive equipment;
- Physical handling involved in oral motor practice and feeding activities (breakfast, lunch, snacks);
- Toileting requiring the transfer of students to and from wheelchairs or other adaptive equipment;
- Carrying out required range of motion and relaxation exercises with individual students.
- As a part of handling and positioning, your goals and considerations with the student should include:
 - Obtaining greatest degree of motor skill possible
 - Facilitating as much active participation from the student as possible
 - Facilitating quality, active movement
- As part of the handling and positioning process, your goals for yourself should include:
 - Normalizing muscle tone before demanding active control;
 - Learning by feeling desired movement;
 - Having stable base from which active movement can occur;
 - Breaking up total body responses and develop isolated active control of specific body parts.

What to Ask

- If the individual is unable to tell you what position is best for a given situation, ask those who will know (parents, family, etc.) *Don't* assume you know what's best.
- Remember to make sure the individual is included in activities. Don't allow him or her to be excluded because he or she is out of the range of vision or hearing because someone forgot to reposition the individual. Ask ahead about the plans for the group so the individual can be positioned appropriately.
- Find out what the location options are for meals. Ask the individual (or family) what location will work best for them.

Section 3

Bowel Care

Bowel care includes promoting the student's usual pattern of bowel functioning. This may involve following the plan established by the student's parents and/or caregiver, physician, or other health care professional in the community. Staff may be involved in initiating a plan to promote adequate and regular bowel func-

tioning. Factors that contribute to optimal functioning include a high-fiber diet, adequate fluid intake, scheduling for elimination at regular times each day, possible planning for toilet training, providing a conducive environment, proper positioning for elimination, and physical activity or exercise.

Equipment Needed

- An adapted toilet chair
- A special toilet chair constructed to sit over the toilet
- A stool for the individual's feet may be used
- A support bar for the individual to grasp

Student Considerations and Accommodations

- If an individual has trouble chewing and swallowing, and needs an increase in fiber content in his or her diet, this may be difficult. The individual may need to eat blended, pureed, or baby foods, but commercial baby foods contain very little fiber, so table foods can be placed in a baby food grinder or food processor to obtain the best texture for the individual with oral-motor impairment. One can also mix unprocessed bran in food each day to supply additional fiber.
- Individuals need one to two quarts of fluid a day. This fluid should consist of as little sweetened or carbonated beverages as possible. Prune juice has a natural laxative effect and can be combined with another fruit juice to taste more appealing.
- In an effort to develop a schedule of elimination with the individual, Some strategies for promoting the individual's normal schedule of elimination include placement of the individual on the toilet after meals and snacks to take advantage of the gas trocolic reflex that usually occurs after meals. Whatever pattern is established at school should be communicated to and agreed upon with the family. The goal is to provide as much consistency for toileting patterns throughout the individual's day and week as possible. The method used for toilet training must be appropriate and individualized for the individual, with the individual's family and school staff working with him or her.
- If the individual doesn't have control over elimination of feces, staff will need to check the individual's underclothes or incontinent wear often. Determine with the individual and the family how this can best be done. Also ask the individual and the family about the condition of his or her skin. If skin is very sensitive, staff may need to check more often to avoid sores.
- To facilitate defecation, make sure to position the student carefully and offer a conducive environment (you may need to ask

the individual or family what works best for the individual). The individual may have special techniques that may facilitate defecation, such as leaning over in order to push down by blowing up a balloon, blowing bubbles, coughing, or pressing on the abdomen. Digital stimulation of the rectum may be needed to initiate defecation. This procedure should be done only with the guidance of qualified health personnel.

- Proper positioning on the toilet seat may facilitate defecation. A squatting position best facilitates defecation. When an individual cannot sit up alone or assume a position similar to squatting, his or her head and trunk can be elevated with the hips flexed at 90°. An adapted toilet chair may be needed if the student has difficulty with balance or trunk control. The paraprofessional who helps in these activities must be sure to carry out thorough hand washing afterward to prevent bacteria from spreading to other individuals or school staff. Hand washing after assisting with toileting must be carried out in a sink that is not used for food preparation.
- The physical therapist or physician may have developed an exercise program to help the individual be able to eliminate more regularly.
- There are two warning signs that may indicate problems for the individual: diarrhea and constipation.

Diarrhea is defined as watery, copious bowel movements that are usually green in color and have a foul odor. Characteristics of diarrhea include a noticeable or sudden increase in the number of stools; change in consistency with an increase in water content; and a tendency for stools to be greenish in color. Diarrhea may also be caused by diet, medications, milk allergy, food poisoning, parasitic infections, obstruction of the intestine by a large mass of hard stool, or other illnesses. When determining whether the student has diarrhea, consider the number and size of stools in a twenty-four-hour period; the consistency and color of stools; and the presence of other signs such as fever, irritability, cold, cough, lethargy, decreased appetite, vomiting, and abdominal pain. The family should be notified. One of the major concerns with diarrhea is the risk for developing dehydration.

Constipation is the retention of feces in the intestinal tract or a delay in excretion of feces from the rectum. Constipation exists when the interval between bowel movements is greater than the time normal for the individual, when the volume is small and feces remain in the rectum, and when the consistency of feces is hard and dry. Constipation is generally restricted to situations in which an individual has fewer than three bowel movements per week. A change in the frequency of stools is more significant than the frequency itself. In addition to the change in frequency, size, and consistency of stools,

other signs of possible constipation are abdominal pain, enlargement of the abdomen, nausea, decreased appetite, no appetite, or painful defecation.

Constipation is often caused by a low fiber diet, inadequate fluid intake, dehydration, malnutrition, voluntary withholding of feces, defective innervation of muscles as in spina bifida and paraplegia, decreased muscle tone as in Down syndrome and cerebral palsy, and side effect of certain medications. Increasing fiber in the diet often aids in relieving constipation, as does increasing the intake of fluids; promoting a normal bowel pattern; minimizing the number of distractions while toileting; positioning properly on the toilet seat; ensuring that physical activity occurs as allowed; and using suppositories, laxatives, or enemas (only if prescribed by a physician, nurse practitioner, or clinical nursing specialist).

What to Ask

As a paraprofessional working in the health office you may be called upon to help with toileting, bowel movements or related concerns frequently. It's important for you to know the warning signs of constipation and diarrhea so you can ask the individual and staff members for symptoms of possible problems. Always ask the individual, when helping him or her with toileting or what is needed from you and be as accommodating to his or her needs as possible. Treat the person carefully, respectfully, and discretely.

Section 4

Cast Care

Cast care means helping an individual who has a cast on a body part to keep it in good condition, and prevent additional problems to the individual's body while wearing the cast. Four major requirements are included in cast care: protecting and cleaning the cast; assisting the student with a cast in toileting activities (if necessary); checking the condition of the skin around and underneath the cast; and checking for the continued correct positioning of the cast.

Equipment Needed

- Cleaning the cast requires a mild abrasive cleanser and water.
- Plastic wrap to keep those areas that are susceptible to soiling clean.
- A flashlight is needed for determining whether the area underneath the cast is free of foreign objects.

- For individuals in a hip cast, a bed pan and urinal (for males) are required instead of the usual toileting facilities.
- Alcohol is used on the skin surrounding the edges of the cast to reduce the likelihood of the skin being injured.

Student Considerations and Accommodations

- Maintain cast care with the individual so he or she can participate in as many activities as possible.
- Daily cast care involves care of the new cast, preventing cast soiling, bathing the individual with a cast, managing the activity of the individual with a cast to prevent any harm or injury to the individual as a result of wearing the cast, and monitoring the fit of the cast.
- Monitor the individual's behavior closely with a new cast for the first seventy-two hours so he or she doesn't "dent" the cast. This would cause pressure under the cast.
- Monitor the individual so he or she doesn't get the cast dirty. This can be done by covering the cast (like during meals) with a plastic bag. If the cast becomes dirty, it can be cleaned with any mild abrasive cleanser and a slightly damp cloth. The cleansing powder is rubbed into the cast to remove the soil, lightly rinsed, and the cast is allowed to dry.
- If you're involved in bathing an individual in a cast, remember first, the cast must remain dry. A sponge bath is the best alternative to preventing the cast from getting wet.
- Monitor the individual's activity. Tell him or her to watch for food falling into the cast, or moisture around the cast. If an individual cannot verbalize discomfort at certain points on the cast, watch his or her behavior to see if you notice some kind of change that could indicate sore skin, etc.
- Checking the student's circulation includes checking the fingers or toes of the casted limb for color, proper temperature, presence of any swelling, and capillary filling. If all is well, the fingers or toes will be pink in color and warm to the touch. There will be no swelling in comparison with those on the other limb.
- Check the sensation to touch and movement routinely to evaluate determine the fit of the cast. The sensation and movement can be examined by touching the toes, fingers, and so forth. If the individual moves or wiggles the toe or fingers when they are touched, sensation is present.

What to Ask

- Ask the individual if he or she is having pain or discomfort from the cast. If there's more pain than is expected, the family

should be notified.

- Ask the individual if there's any problem with the cast, such as wetness or something falling into the open ends.
- When the individual first gets the cast, help him or her adjust to position and help make any necessary modifications or accommodations in the environment.

Section 5

Diapering

Changing diapers in a sanitary manner is an important way providers can prevent the spread of infectious organisms. Germs found in the stool can be spread by the hands of staff or individuals, or through contaminated food, water, objects, or surfaces. Many diseases can be spread by contact with stool. These include infections caused by bacteria (Salmonella, Shigella, Campylobacter, etc.), parasites (Giardia, pinworms, etc.), and viruses (rotavirus, Norwalk virus, and hepatitis A). You can help prevent illness by following the diapering guidelines described below.

Basic Principles

- Change diapers only in a designated diapering area.
- Separate diapering area from the food storage, preparation, and eating areas.
- Dispose of soiled diapers properly.
- Wash hands (staff and individual) after diapering.

Equipment Needed

Changing Surface

- Keep the changing surface away from other individuals, and preferably three feet from the floor.
- The surface should be a smooth, moisture-resistant, easily cleanable material.
- For extra protection, use non-absorbent, disposable paper (computer or roll paper) under the individual.

Hand washing Sink and Supplies

- The best hand washing sink is one equipped with both hot and cold running water mixed through one faucet (hot water temperature not greater than 120° F).
- Water controls ideally should be foot, knee, or operated to avoid contamination of hands.

- The sink should be next to the changing surface and separate from the food preparation sink.
- Keep liquid soap, paper towels, and fingernail brush within reach.
- Use single-use, disposable paper towels instead of cloth towels.
- Turn off faucet handles with wrist or a disposable paper towel.

Diapers

- High-absorbency disposable paper diapers are preferred because cloth diapers leak more and require more handling (the more handling, the greater chance of infection).
- All diapers must have an absorbent inner lining completely contained within an outer covering made of waterproof material that prevents the escape of feces and urine.
- For cloth diapers, the outer covering and inner lining must be changed together at the same time. Outer coverings must not be reused unless they are laundered.
- Ask your health consultant for approved procedures for the use of cloth diapers, if used.

Disposable Gloves

- Gloves should be worn when changing the diaper of an individual with diarrhea or a known infection that is spread through the stool.
- Pregnant women or women considering pregnancy may want to wear gloves when changing any diaper.
- Gloves should be worn by staff if they have open cuts, sores, or cracked skin, or if the individual has open areas on the skin.
- Discard gloves and wash hands after each diaper change.

Disposable Wipes

- Pre-moistened wipes must be dispensed in a manner that prevents contamination of the wipes or the container.
- If this is not possible, each individual should have a separate container of wipes, labeled with his or her name, and only used for that individual.

Skin-care Items

If skin-care items are used, keep them within the provider's reach, and out of the reach of children. Each individual must have his or her own labeled container of skin care products. Parents or the individual must provide written and signed directions and permission to use these products. Use skin-care items according to package directions.

- **Plastic bags:** Use disposable plastic bags to line waste containers and to send soiled clothing or cloth diapers home. Store

plastic bags out of any children's reach.

- **Waste container:** Use a tightly-covered container with a foot-operated lid. Keep the container away from individuals. Line the container with a disposable plastic trash bag. Empty container before full and at least daily, and clean it with detergent and disinfectant daily.
- **Toilet-training chairs:** Flush toilets are recommended rather than toilet-training chairs. If used, chair frames should be smooth and easy to clean. If toilet-training chair are used they must be emptied, cleaned with detergent and water, and disinfected after each use.
- **Cleaning supplies:** Use disposable gloves and towels, cleaning solution (detergent) and disinfecting solution (bleach).

Prepared by Hennepin County Community Health Department with support of epidemiologists and child care consultants from the Minneapolis/St. Paul area state and local health departments, March 1993.

Steps to Follow When Diapering

It's possible to spread infection when changing diapers, so perform the procedure carefully. Before you change a diaper, have the necessary equipment on hand. When changing the diaper, follow this step-by-step procedure.

- Use disinfectant for cleaning the changing table.
- Place the individual on a clean changing table or other appropriate surface. Do not leave the individual unattended.
- Remove the soiled diaper and place it in double bagged plastic in a covered pail. If the diaper is cloth and soiled with feces, leave it on the changing table until the individual leaves the area.
- If other clothing is soiled, remove it and place it directly into an identifiable plastic bag which can be secured and sent home or to the laundry.
- Cleanse the perineum (area between the buttocks and rectum) and buttocks thoroughly with soap and water. Use ointments and powders only when authorized and provided by a parent.
- Rinse and dry the skin before applying the clean diaper.
- Have the individuals return to what they were doing or assist him or her in returning.
- While wearing disposable plastic gloves, rinse and wring out in the toilet any cloth diaper soiled with feces. Use only disposable diapers unless the physician orders cloth diapers for a specific reason.

- After rinsing, place cloth diapers in appropriate receptacle.
- Remove gloves, discard them in an appropriate receptacle.
- Wash your hands after wearing gloves.
- Report abnormal conditions to appropriate person. Abnormal conditions may be:
 - Blood or streaks of blood on diaper
 - Watery, liquid stool
 - Mucus or pus in stool
 - Clay-colored stool
 - Skin rashes
 - Bruises or breaks in skin.
- Use a disinfectant to clean the changing table. Household bleach and strong chemical cleaners work well.

Adapted from *Managing the Student with Chronic Health Condition: A Practical Guide for School Personnel* by Pathfinder and the School Nurse Organization of Minnesota, 1986.

Section 6

Diet Monitoring

Common nutritional problems result in disorders in growth and weight gain. These may often be caused by poor eating skills or eating habits, or other unrelated factors. Diet monitoring involves helping the individual eat the right foods at the right times to maintain healthy weight, skin, and proper elimination. Some examples of conditions where diet has not been monitored appropriately are:

- Slower than expected linear growth might indicate that an individual is malnourished, has a chronic disease (e.g., kidney or heart disease), an endocrine problem, or a genetic or chromosomal abnormality (e.g., Down syndrome).
- Lack of appropriate weight gain a common problems found in individuals with special health care needs. Slow weight gain usually results from inadequate intake of calories. This may be due to poor appetite as a side effect of medication, feeding problems, or chronic illness. Inadequate intake of calories can cause an individual to be irritable and withdrawn. It can delay linear growth, motor abilities, and learning capacity.
- Children who gain weight too fast are more likely to be overweight as adults. This can lead to a number of health problems, including high blood pressure, diabetes, cancer, and heart disease. In addition, very young children who are obese

can show delayed gross motor development due to the extra fat their muscles must support. A number of individuals with disabilities have a tendency to be overweight, including those with Down syndrome, Prader-Willi syndrome, or spina bifida.

Equipment Needed

The equipment needed will vary depending on the type of diet monitoring taking place. Check each individual's diet plan and requirements for the equipment needed.

Student Considerations and Accommodations

- If you're working with an individual who is tube fed, this doesn't necessarily preclude oral feeding, but consultation with the physician or family will determine the quantity, type, and timing of oral feedings.
- Part of diet monitoring might involve dealing with an individual who has problems with constipation which is a very common problem. It can occur due to a number of factors including the individual's neuromuscular problem, inadequate fluid or fiber intake, lack of exercise, and/or drugs that decrease intestinal motility. If this occurs, refer to the section on constipation in the bowel care section, to help the individual deal with this problem.
- Other factors you may be involved in with dietary issues are gagging, vomiting, or rumination often resulting from over-feeding, food intolerances, improper feeding techniques, or gastrointestinal abnormalities. Occasionally an individual will gag or vomit to control his or her environment. Gagging, vomiting, or rumination can alter the acid-base balance of the body, cause irritation to the throat and mouth, and destroy the enamel on the teeth. If this should occur, try to talk to the individual to find out what is happening and why. Try to adjust the environment to accommodate the individual.

What to Ask

- If you notice that an individual's behavior seems to change and there doesn't seem to be any obvious reason, question the diet.
- If an individual has trouble eating with others or in certain environments, explore this with the individual and his or her family to modify the environment when needed.
- When the health office is to monitor the diet of an individual, make sure specific instructions are given in writing.

Adapted with permission from the authors from *Health Care for Students with Disabilities: an Illustrated Medical Guide for the Classroom* (1990), J. Graff, M. Mulligan-Ault, D. Guess, M. Taylor, & B. Thompson. Baltimore, MD: Paul H. Brookes.

Section 7

Glucose Monitoring

Individuals with diabetes have an imbalance of the amount of glucose in the blood. When this happens the individual can have behaviors that can affect his or her ability to concentrate and learn, or, in the worst case, can result in a coma and/or possible death. Glucose monitoring is a procedure that identifies the amount of glucose (sugar) that is present at any given time in the blood. Individuals will often have to check their glucose level during the work or school day. If the individual has an imbalance when the glucose is checked, then insulin must be administered. For more in-depth information about diabetes, refer to Chapter Eight.

Equipment Needed

Depending on the type of monitoring the individual uses, these may be types of equipment used.

- Alcohol pads
- A lancet
- A reagent strip (a small plastic with a pad on one end that changes color after exposed to blood)
- Glucose monitoring device

Student Considerations and Accommodations

- Most often individuals are encouraged to self-monitor blood glucose as part of their routine needs associated with insulin. This is especially encouraged for individuals who receive several insulin injections a day. Therefore, many are now taught how to check their own blood levels. You will probably be the location for their equipment to do this and to monitor the individual and the monitoring of blood glucose.
 - If the individual doesn't have the coordination to perform the glucose monitoring for him- or herself, you will probably be called upon to do this during the day. The frequency will depend on individual need. That should be clearly stated in the individual plan for him or her.
 - Help establish a reasonable schedule during the day for the individual based on the daily activities and his or her need.
 - Provide the privacy needed for the individual (or you) to monitor injections.
 - Help the individual remember to record the glucose level in a log or record. You may need to help do the recording for him or her.
-

- Watch the individual for signs of insulin reaction such as: shaking, sweating, dizziness, paleness, irritability, confusion, poor coordination, headaches, double or blurred vision, or numbness or tingling of the lips. If these occur, the individual should eat a snack containing fast acting glucose like a small box of raisins, a half cup of soda pop or fruit juice, or five small sugar cubes.
- If the individual is ill, the amount of physical activity and food should be decreased. The insulin dosage may need to be adjusted. Check this out with the individual and the family if you feel the individual is ill and occurs.

What to Ask

- Ask the individual what level of independence they are able to perform in their own glucose monitoring. If you're unsure whether this is accurate information, ask the licensed school nurse.
- Ask the individual what type of assistance they want from you. Respect the answer.
- Ask the individual or licensed school nurse what restrictions the individual should have in terms of activity, and food. Keep a record of this.
- Ask the individual if he or she has explained his or her situation to the person they spend the majority of the day with (teacher, co-worker, supervisor). Encourage him or her to do so.

Adapted with permission from the authors from *Health Care for Students with Disabilities: an Illustrated Medical Guide for the Classroom* (1990), J. Graff, et al. Baltimore, MD: Paul H. Brookes.

Section 8

Hand Washing

Hand washing is the single most effective way to prevent the spread of infections. Hands are warm, moist, parts of the body that come in frequent contact with germs that cause contagious illnesses. Young children have not yet learned healthy personal habits; they suck their thumbs, put things in their mouths, and rub their eyes. Many individuals also like to handle animals and pets, which often carry a variety of germs. These habits can spread disease. Germs are easily spread when hands touch people, pets, and objects.

Caregivers must learn why, when, and how to correctly wash their hands and the individual's hands. Included in this section

are instructions on how and when to wash hands, for both staff and individuals, and pictures to demonstrate the correct hand washing procedure. Babies' hands can be washed with soap and running water using the same procedure that is used for older children and adults.

Soap

Liquid soap should be used in because often individuals do not have the dexterity to handle a bar of soap. Soap doesn't have to be antibacterial to be effective. It's the physical action of hand washing that removes soil.

Fingernails

It's important to keep fingernails short and clean. Fingernail brushes are effective in removing stool from under nails.

Gloves

- Gloves are *not* a substitute for hand washing.
- Single-use gloves must be disposed of after each use, and hands must be washed.
- Gloves should be worn by staff if they have open cuts, sores, or cracked skin, or if the individuals they are working with has open areas on the skin.
- Gloves should be worn when changing the diaper of an individual with diarrhea or a known infection that is spread through the stool.
- Pregnant women or women considering pregnancy may want to wear gloves when changing any diaper.
- Gloves *must* be worn for handling blood (nosebleeds, cuts) or items, surfaces, or clothing soiled by blood or bloody body fluids. Wear gloves when cleaning bathrooms, diapering area or any areas contaminated with stool, vomit, or urine.
- Either single-use or utility gloves may be used for cleaning and disinfecting contaminated items or areas.

Adapted from materials developed by Hennepin County Community Health Department with the support of the epidemiologists and child care consultants from the Minneapolis/St. Paul area state and local health departments, March, 1993.

Section 9

Skin Care

Skin reflects a condition of health. Important components include: a color that is normal for the individual, a smooth texture, no swelling, adequate elasticity, and sensation present to the degree that is normal for the individual. Healthy skin is characterized by having no bleeding or bruising; not being excessively oily or dry; having no breaks such as scratches or lacerations; and having no pressure sores, burns, or rashes.

Preventing skin breakdown is essential for those individuals who must remain in a wheelchair or in other positions for extended periods. It's far easier to prevent skin breakdown than to heal pressure sores. You will work with the LSN to implement procedures to prevent and/or treat skin breakdown.

Equipment Needed

- Gauze
- Ointments
- Alcohol

Student Considerations and Accommodations

- When promoting healthy skin in the individual with disabilities, consider discussing with the individual the student's degree of bladder and bowel control, nutritional status, level of activity, ability to distinguish sensations, and ability to communicate to others the sensations experienced. An individual who has limited control over bladder and bowel functioning needs a lot of support to have healthy skin.
- If the individual wears wet or soiled clothing the skin will not remain dry or clean. The constant presence of moisture can promote the growth of bacteria on the skin which can lead to infection. Help the individual express his or her needs in this regard so that skin conditions don't get out of hand.
- Based on the LSN's nutritional assessment, the SHP may work with the family to try to promote a healthy diet. Make suggestions about healthy foods the individual can buy, order, or cook that he or she would like to eat.
- Encourage the individual to be as active as possible. Exercise and activity will promote healthy skin. Brainstorm about ways the individual can be active, in spite of his or her disability.
- If the individual is in a wheelchair, remind him or her how important it is to be repositioned every so often to avoid pres-

sure sores. Set up a schedule with him or her for this to be done if help is needed.

Pressure Sores

Pressure sores develop in the following stages:

- Initially, pressure on the skin causes a reddening that disappears as the pressure is relieved. Such reddening often doesn't disappear after prolonged pressure is relieved. The skin becomes hardened and warmer than surrounding skin.
- A pressure sore develops where the skin continues to be reddened, hardened, and warmer than surrounding skin. The epidermis becomes broken and the dermis is exposed.
- In the third stage, an open sore develops as the dead tissue separates from the living tissue. The skin around the sore continues to be reddened and hardened and warmer than surrounding skin and there is drainage from the open sore.
- In the last stage, the open sore becomes deeper and has a foul smell. There may or may not be drainage present.

What to Ask

- Ask the individual if he or she has any allergies that may be causing the condition. Report allergies to the LSN or note them on the health record or emergency card.
 - Help with skin care problems may require changing dressings. Ask the individual what help and support he or she may need in this. Make sure you know when these changes should take place. This information should be available on the IHP.
 - Report any skin concerns to the LSN. Optimal levels of activity may be encouraged as part of a proactive skin care program on the IHP. Decreased activity can result in increased opportunities for the student to experience pressure on skin surfaces.
 - The skin underneath braces and splints or wheelchair seats should be checked *daily* or as noted in the IHP to identify persistent red spots. Ask the individual if he or she has noticed any sores and make sure he or she is moving and shifting in the chair often. If the individual cannot initiate movement to relieve the discomfort, methods need to be included in the IHP to assist the individual in communicating with others.
 - If a pressure sore is being treated, it needs to be written on the IHP by the nurse. Ask for adequate supplies to perform the treatment. Eliminating pressure from the sore to prevent further breakdown is of utmost importance. A regular schedule for repositioning the individual will be established using those positions that best allow the student to continue with other activities while avoiding pressure on the existing sore and sustained pressure on other areas at risk of developing sores.
-

- Observe the healing process and report to the LSN. Ask individuals how they feel and if they seem to be healing. If an individual has a sore that doesn't heal and that progresses in size, the potential for blood poisoning exists. This condition indicates that bacteria have entered the blood stream. If not treated with antibiotics, the infection can progress and cause an overwhelming infection and death.

Parts of this section were adapted from *Health Care for Students with Disabilities: an Illustrated Medical Guide for the Classroom*. J. Graff, et al., Baltimore, MD, 1990, Paul H. Brookes Publishing Co. Reprinted with permission from the authors.

Section 10

Toileting Procedures with Individuals Who Use Wheelchairs

Individuals who need help toileting may each have their own way of completing this task. You can follow these suggested steps for helping an individual out of the wheelchair and onto the toilet:

- The SHP should wash his or her hands at both the beginning and end of toileting.
- Wheel into stall.
- Lift and swing tray away.
- Position chair next to toilet.
- Lock brakes.
- Unfasten seat belt.
- Unfasten pants.
- Push pants down to buttocks.
- Lift buttocks off chair seat (doesn't need footrest to push up on for pants down).
- Push pants down over buttocks to knees.
- Lower hips to chair seat.
- Push underwear down to buttocks.
- Lift buttocks off chair seat.
- Push underwear down over buttocks to knees.
- Lift buttocks off chair seat.
- Lower hips to chair seat.
- Swing away footrest (reposition chair as necessary).
- Right arm grabs bar.

- Left arms hold the left wheelchair armrest, then toilet seat.
- Reach down to toilet seat with right arm.
- Pull self forward in chair.
- Feet on floor pull forward & pivot onto toilet.
- Position self securely on toilet (doesn't use footrests to push pants down).

These steps should be followed to move from the toilet back to the wheelchair:

- Provide any necessary assistance in wiping.
- Flush toilet.
- Pull underpants and pants up over knees.
- Grab transfer bar with right arm.
- Reach across and grab chair seat with left arm and pull self forward.
- Feet on ground, pull forward and up; pivot into chair.
- Hold onto chair armrests with each hand and position self securely in chair.
- Unlock brakes.
- Wheel back from toilet (far enough to clear swinging footrests).
- Lock brakes.
- Swing footrests into place (pull pants up from underneath shoes if necessary).
- Pull underwear up as far as possible.
- Lift buttocks off seat (by pushing with leg and arms).
- Pull underwear up over buttocks to waist.
- Lower hips to seat.
- Pull pants up as far as possible.
- Lift buttocks off seat.
- Pull pants up over buttocks to waist.
- Lower hips to seat.
- Straighten underwear and pants if needed.
- Assist tucking in shirt.
- Fasten pants.
- Fasten seat belt. Be sure hips are all way back in chair so trunk is vertical and no greater than four inches of thigh are forward of chair seat.
- Swing tray back into place.
- Unlock brakes.
- Wheel out of stall.

Summary

Along with learning about disabilities, it's also essential that SHPs know special personal care skills to help meet the needs of the individuals with whom they work. The skills included are those often used in caring for individuals with a disability. These skills will be demonstrated and practiced in class. The LSN you work with will provide you with a review of the skill and the opportunity to re-demonstrate the skill. The SHP may perform some of the skills as part of his or her job responsibility. Others of them are delegated from the LSN. With good communication and understanding, the LSN and paraprofessional will provide safe, quality care for their clients.

Questions to Ponder

- Safety is a primary factor in performance of personal care skills. Why?
- If your child had a disability what would you (as a parent) expect of the LSN and SHP?
- Of the skills discussed, which two are the most essential for your safety and the individual's safety? Why?

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Chapter Ten

Selected Health Procedures: Specific Instructions

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Introduction

The following are brief descriptions of additional types of care that you may eventually provide for individuals. These are all types of care that should only be given after receiving specific instruction and training from the supervising nurse. For that reason, these descriptions are provided as background information only.

Section 1 Catheterization

An individual may have a catheter inserted for many different reasons. Urinary catheterization is often done to:

- Relieve urinary retention.
- Obtain a sterile urine specimen.
- Measure the amount of residual urine in the bladder.
- Obtain a urine specimen when a specimen cannot be secured satisfactorily by other means.
- Empty the bladder before and during surgery and before certain diagnostic procedures.

A catheter that will remain in place is called an *indwelling retention*. The majority of the time an indwelling catheter is placed temporarily. An indwelling catheter consists of a long, narrow, flexible tube with two holes in the end that is inserted into the bladder. This same end has an area that inflates to the size of a very small balloon when filled with sterile water. The sterile water is injected via a pre-filled syringe through a lumen on the distal end of the catheter specifically made for this purpose. The indwelling catheter is connected to wider tubing which is attached to a plastic bag that serves as the collecting container for urine.

An individual who requires catheterization during school has a scheduled time to do this. He or she will need a private area for the catheterization with a sink for proper cleanliness. Catheterization procedures differ for males and females and from person to person. Some individuals catheterize themselves and won't need the SHP to facilitate the procedure. The procedures include positioning, cleansing the area, insertion of the catheter, draining the bladder, removing the catheter, and clean-up.

Section 2

Colostomy and Ileostomy

A colostomy or ileostomy provides a way for a person to eliminate feces without passing it through the rectum. Whether a person has a colostomy or an ileostomy is determined by the portion of the intestinal tract that has been involved in disease, disability, or accident. A colostomy or ileostomy is performed when there has been obstruction or blockage in the intestines and passage of the contents in the intestines is prevented. Either a colostomy or an ileostomy may be temporary or permanent. After a colostomy or ileostomy have been surgically performed, the individual no longer has the ability to retain feces in the rectum or pass feces through the rectum and out the anus. Feces are, instead, eliminated through a hole called a *stoma* that is created through an opening in the abdomen. A pouch is attached over the stoma for collection of fecal material as it is eliminated from the intestines.

Care for persons with colostomies or ileostomies is usually provided at home. If students need assistance at school, the SHP should refer to the IHP implement the planned activity, notify the LSN, and record the action taken.

Section 3

Oxygen Therapy

Oxygen may be ordered by a physician to help an individual breathe. Depending upon the individual's condition, the physician will determine how much oxygen the individual should receive. Many individuals may require oxygen in home, at school, or work. Some of these individuals may have infections involving the lungs, (for example: pneumonia), loss of lung elasticity, loss of functioning lung tissue due to disease, diseases of the nervous system (for example Guillan-Barre, multiple sclerosis, etc.)

The health paraprofessional *does not* administer oxygen.

To help prevent fires the following precautions should be taken when using oxygen:

- Store oxygen tanks in an upright position in a cool area.
- Keep oxygen away from heat and electricity.
- Do not smoke when oxygen is in use.
- Place "No Smoking" signs in conspicuous places.
- Open flames, such as candles, matches, or stoves aren't allowed.
- Avoid use of flammables such as oils, alcohol, synthetic clothing, and wool blankets.

- Check to see that the electrical equipment used in the room is in good working condition and doesn't emit any sparks.
- Turn off flow regulators when they aren't in use to avoid oxygen leaks. (This should be done only if the health paraprofessional has been taught by the supervising health nurse.)
- Keep fire extinguishers available and in proper working order.
- Use of a humidifier will help reduce static electricity and the drying effect of oxygen.

Section 4

Respiratory Therapy

Individuals sometimes receive a form of respiratory therapy called *intermittent positive-pressure breathing* (IPPB) which provides a specific amount of air, oxygen, water, or medication under increased pressure to the respiratory tract. This device forces deeper inspiration by positive pressure inhalation and then permits passive exhalation. The pressure varies according to the person's needs. Assisted ventilation is used for persons who have respiratory disorders when periods of deeper inhalation would be helpful to further aerate the lungs or to move secretions. Pressure for the IPPB is supplied by the machine, which uses compressed air or oxygen. The air or oxygen is forced through a nebulizer containing distilled water or medication. The person who is having assisted ventilation inhales the mist through a mouthpiece or face mask. In many instances the person controls the rate of the machine by his breathing; in others the rate is controlled by the machine. Treatments are usually done twice a day, in the morning and at night.

The SHP doesn't administer respiratory therapy, but may be asked to provide skin care for persons who use a nasal cannula or mask. Water soluble lubricants can be applied to the skin – oil based lubricants can damage the mask or tubing. New tubing can add to the individual's comfort: encourage the individual or his or her family to change tubing on the recommended schedule.

Section 5

Tracheostomy

A tracheotomy is an incision into the trachea or windpipe, performed to create an opening in the trachea to accommodate a tube thorough which the individual will breathe. A tracheotomy is usually done to provide an airway that bypasses an obstruction in

the upper respiratory area.

The tracheostomized person is unable to speak, unless the tracheostomy tube is closed off. People with tracheostomies may initially be very frightened and anxious and need a lot of support and reassurance that their needs will be met promptly and efficiently. Other means of communication are necessary between the individual and others.

Once the opening has been made into the throat, a curved tube called a *cannula* is inserted and remains there to keep the airway open. The cannula may be metal or plastic and consist of either one or two tubes. Some persons who have had a tracheostomy for a very long time may have only an open hole in the neck area that remains open on its own. Since the tracheostomy tube serves as the person's airway, care must be taken to prevent the inspiration of foreign material into the unprotected tracheostomy tube. For this reason cotton balls, loose threads from gauze, or other foreign bodies must be kept away from the tracheostomy opening. Because the nasal passages are bypassed, the normal humidification process must be artificially provided for the person with a tracheostomy. This is usually accomplished by a humidifier or attaching a humidifying device.

The person with a tracheostomy may lead a normal life and become involved in almost any activity, except swimming.

The tracheostomy tube is usually held in place by two ties that attach to the sides of the tube. If there are complaints of discomfort around the tube or from the ties, the health paraprofessional should report them to the supervising health nurse. There may or may not be a dressing around the tracheostomy. An emergency care plan will be completed with activities for the SHP and/or other school staff to follow should the tracheostomy tube become dislodged.

Section 6

Tube Feeding

There are many reasons why individuals with disabilities may not be able to eat by mouth, some of which include inadequate sucking ability, extreme difficulty chewing and swallowing, or frequent episodes of pneumonia resulting from stomach contents or formula being drawn into the lungs. There are two types of tube feeding described here: nasogastric tube feeding and gastrostomy tube feeding.

A nasogastric tube (NG) is extended through the nose, down the esophagus, and into the stomach. The individual receives nutrients in a liquid form through this tube. This type of tube is used as a short-term intervention. Liquid nutrients may be passed

through the NG by one of two methods: the bolus method, which allows the flow to happen within a few minutes, or the intermittent gravity drip method which allows formula to drip slowly over a twenty to thirty minute period from a hanging container. These two methods are used when individuals can tolerate fairly large amount of fluid nutrients over a relatively short period of time.

A gastrostomy tube is extended directly through the abdomen into the stomach. The individual receives liquid nutrients through this tube, as he or she would through the NG tube. The gastrostomy tube is really a polyurethane or silicone tube that is soft and flexible and about eight to twelve inches long. The tube is inserted through the abdomen wall into the stomach and is held in place by suture. A clean gauze dressing is often taped around the tube to protect the opening and absorb any leaking. If this irritates the skin, the gauze is not used. If a button gastrostomy is used, a short tube is inserted into an established opening in the stomach. The button fits closely to the skin on the abdomen and has a small plug that is removed for feedings.

The difference between the NG and the gastrostomy tube is that the purpose for the gastrostomy is long-term or permanent feeding, not short-term feeding as with the NG. Liquid nutrients may also be passed through the gastrostomy tube by one of the two same methods as the NG: the bolus method, which allows the flow to happen within a few minutes, or the intermittent gravity drip method which allows formula to drip slowly over a twenty to thirty minute period from a hanging container. These two methods are used when individuals can tolerate fairly large amount of fluid nutrients over a relatively short period of time.

Section 7

Ventilators

Any individual with a condition that alters his or her ability to breathe independently may require ventilatory assistance. Ventilators breathe for people until they can breathe on their own. Ventilators have most often been used with persons in the intensive care unit (ICU) of the hospital. Now ventilators are also used as a means of respiratory support in home, work, and schools.

Persons who require a ventilator may be those who have conditions such as pneumothorax (collapsed lung), ARDS (adult respiratory distress syndrome, where parts of the lung become increasingly stiff and noncompliant), COPD (chronic obstructive pulmonary disease, where lungs are chronically overinflated and inelastic), persons who hypo-ventilate after thoracic or abdominal surgery; persons who may be obese or debilitated; persons with nonfunctioning respiratory regulatory mechanisms.

The SHP will not work with the ventilator without training and supervision from the LSN.

Adapted with permission from the authors from *Health Care for Students with Disabilities: an Illustrated Medical Guide for the Classroom* (1990). J. Graff, et al. Baltimore, MD: Paul H. Brookes.

Summary

The select health procedures discussed in this chapter are those that may be delegated to the SHP from the LSN. Each situation will be assessed and evaluated separately. (Refer to the chapter on delegation to review the importance, responsibility, and legal implications of nursing delegation.) Since the individual's needs have to be met regularly, these procedures are often done in school and they're usually performed by the nurse. These procedures have been included here to provide basic information about the procedure and to increase awareness and understanding of both its necessity and steps required to carry it out. Having this knowledge will help the SHP understand the individual's needs and will provide a basic understanding if the LSN delegates the procedure to the SHP.

Questions to Ponder

- Why are these procedures performed by the LSN?
- What issues does the LSN consider if these procedures are delegated to the SHP?
- As a SHP performing these select procedures, what concerns will you have in mind?

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Chapter Eleven

Medication Administration

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Introduction

Medications are used to help a person recover or maintain normal body functions. They can be very strong: medication taken incorrectly may not have the desired results or have serious – or even fatal – negative effects.

The main reasons a health paraprofessional would be administering medications are to relieve symptoms, treat an existing disease, or promote health. Many students with disabilities require medications throughout the school day and wouldn't be able to come to school without help and support with medication.

If delegated by the LSN, the SHP may administer prescription or as over-the-counter (nonprescription) medications when requested by parents. Medications that are prescribed by a physician for a particular individual should never be taken by anyone else. An example of a prescribed medication is penicillin, while Tylenol is a nonprescription medication.

As the SHP, you may administer medications in a variety of ways orally, rectally, topically, in the eyes or ears, and in the nasal passages.

Before administering any medications, review and follow the policies of the school district related to approval and consent for medication administration. These generally include parents' requests to give medication (it's always helpful to talk this over with parents first), physicians' written approval or request for administration of medication, and a secure place to store medications. The medication container must have the individual's name on it, the dosage, the frequency of administration, and the prescribing physician's name. There should be a system for recording what medications and for whom are being kept in the health office at all times.

Section 1

Properly Administering Medication at School

Whenever possible, the parent or guardian should make arrangements so that it's not necessary for school personnel to administer a medication to a student. However, there are cases when a student's health could be compromised by not getting medication during school hours. In response, school districts need written policies and procedures for administering prescribed medications. These help to ensure that the student – who must use medication to treat a disability or illness – will attend school.

Take Care of Preliminaries

After you have been authorized to administer medications by the LSN and have been instructed by the school nurse but before administering any medication, the LSN will:

- Identify students who require medication. The school nurse, principal, teacher and other school personnel should know which students require medications during the day. If the school doesn't have a school nurse, the principal should assume responsibility, with the parents.
- Get a written prescription. Require this from the physician. The prescription should indicate the necessity of administering medication during school hours.
- Get a written statement from the parents. This should request and authorize the designated personnel to administer the medication prescribed by the physician.
- Get a duplicate bottle. Parents should ask the pharmacist to prescribe duplicate bottles of the medication. One bottle should be kept at home, the other at school. Both bottles should contain the name and telephone number of the pharmacy, the student's identification, name of the physician, the name of the medication and the dosage to be given.
- Keep a list of students on medication during school hours in a central place. For each student, include the name of the medication, the medication dosage and times medication should be given. Also include information on why the student is taking medication and the route medication is to be given.
- Let the school nurse supervise medication administration. Medications should be administered under the direct supervision of the school nurse or other health qualified professional. If you, as a health paraprofessional, are the designated person, you should have:
 - Knowledge about the effective use of medications and their side effects.
 - Knowledge of the condition for which the medications were prescribed.
 - The ability to understand coping mechanisms used by students who must take medication more than once a day.
 - The ability to properly administer and record medications given in school.
 - Ability to observe, evaluate and report the student's reaction to the medication in school – including expected or adverse reactions.

To properly administer prescribed medication, the school nurse – or staff member directly supervised by the school nurse – must follow these steps:

- Check the bottle to assure the correct medication is given to the student. Prescribed medication bottles should bear the individual's name; the date the prescription was filled; the name, address, and phone number of the pharmacy; the prescription number; the drug name, dosage, and frequency; physician's name; and any special storage instructions.
- Check the prescription to assure the proper dosage is given in the prescribed way. Make sure it's the right medication for the individual.
- Wash hands before and after administering any medications.
- Inform the appropriate school staff of the potential benefits and side effects of the medication being taken by students.

Administration of Types of Medications

- **Capsules & pills:** Pour directly into a paper cup without touching the medication and assist the individual in getting a cup of water.
- **Liquids:** Shake if required. Pour medication out of the side opposite the label, holding measuring container at eye level.
- **Topical medication for the eyes:** To clean the eyes, use a clean wipe for each eye. Have the individual lie down and look up. Retract the lower lid, approach the eye from behind, outside the field of vision. If ointment, apply gently near the center of the lower lid. If drops, apply gently near the center of lower lid. Do not touch lid with dropper or allow closer than one inch above the eye. Have individual close eyes for two minutes.
- **Topical medication for the ears:** Tilt the head so ear opening is as horizontal as possible. Administer the prescribed number of drops and have the individual remain with his or her head tilted for two to three minutes. If the other ear is also to have drops, wait five minutes and apply them to the other ear.
- **Topical medication for the skin:** Cleanse the area first. Then use clean tongue blade to apply ointment; discard blade, then re-apply a bandage.
- **Suppositories:** Have individual lie down on stomach or on back with knees pulled up, whichever way is more comfortable. Remove suppository from container and generously lubricate it. Expose the anus with one hand and gently insert the suppository with the other. Use the forefinger to advance it once it has passed through the anus but no farther than your first digit. You may have to hold your finger against the anus briefly to prevent the rectum from expelling the suppository reflexively. Make sure the individual is comfortable and instruct him or her to lie quietly for the time indicated.
- **Inhalers:** Help the individual prepare the inhaler. Pressing harder or longer on the activator doesn't change the amount

of medicine delivered. Follow the manufacturer's instructions for administration.

- Record the medication given on the medication record.

Regarding All Medications

- Remember the "six R's" of administering medication – they point to factors you should remember when administering medication to a student: right name (of student); right drug; right dose; right time; right route (by mouth, injection, etc.), and the right record.
- After each administration of the medication, record the date, time, and your signature on the student's medication log.
- If medication is not given, record whether the student was absent, refused, or do not come to the health room.
- Discuss any problems about student compliance with the licensed school nurse.
- Report any adverse reaction noted to the licensed school nurse immediately and take appropriate action. Record on the log what occurred.
- Always return any medication to the locked storage area immediately after administration.
- Injected medications are given only by the LSN.
- School health paraprofessionals administer medications when authorized by a licensed school nurse. The nurse gives guidelines and directions for the health paraprofessional to follow.
- Do not give over-the-counter medications unless the parent requests it in writing and the medication is provided in the original container. *Never violate this rule.*
- Observe, evaluate, and report the student's health status and reaction to the medication at school. Give this information to the parents or guardians – and the student's physician if parents have given approval to do so.
- Store medication in an appropriate place. Keep it locked, and make sure that only designated school personnel have access. If you see any student self-administering medication for which the school has no authorization, report this to the LSN.

Adapted from materials developed by Cyndy Schuster, M.P.H., R.N., C.S.N.P.

Summary

Administration of medication is a nursing task that can seem very easy. However, it's more than just physically giving a tablet or capsule of medication to someone – it includes the responsibility of

understanding the action of the medication's actions, indications, and counter-indications or side effects. Giving a medication to another also carries ethical and legal implications. This procedure, as well as the procedures discussed previously, is often performed by the nurse. The nurse often delegates this responsibility to the SHP and the decision is based on the nurse's judgement.

Questions to Ponder

- What types of medications may the SHP administer with delegation of the LSN?
- What legal issues must be considered when giving medication to another person?
- Minnesota statutes say that schools must have policies for administering of medications to individuals in school. Why is this important?

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Appendix A

People First Language

By Kathie Snow, Parent Assistance Specialist,
Northeast Texas, Fort Worth, PATH Project

Your child is not handicapped. Your child is not disabled. Your child has a disability.

A handicap is an obstacle which society imposes on a person with a disability, i.e., inaccessible transportation or buildings, stairs instead of elevators, no curb cuts where needed, etc.

The Disability Rights Movement is upon us... it had a slow start, but momentum is increasing daily.

Consider this Public Law 94-142, the legislation which guarantees an appropriate education for children with disabilities, was the culmination of a lawsuit filed in 1971 by the Pennsylvania Association for Retarded Citizens on behalf of their children who were not being served by the educational system. PL 94-142 was enacted in 1975. Changes have been occurring, off and on, since that time.

Consider what happened in 1990. In early 1990, the Senate Subcommittee on the Handicapped, chaired by Senator Tom Harkin, (D-Iowa), changed its name to the Senate Subcommittee on Disability Policy.

On July 26, 1990, President George Bush signed into law PL 103-336, the Americans with Disabilities Act (ADA). Notice it was not called the *Handicapped Americans Act*. This sweeping legislation mandates equal opportunities for persons with disabilities, persons who had previously been discriminated against in employment, housing, transportation, and many other areas of daily life.

In 1990, PL 94-142 Congress reauthorized and renamed the Education of All Handicapped Children Act (EHA). It is now PL 103-476, the Individuals with Disabilities Education Act (IDEA).

Isn't it great? But we've still a long way to go. Government cannot legislate morality or values or feelings. Before our children, and others with disabilities, are viewed as truly equal members of our society, our language and our values must be changed. Persons with disabilities must be perceived as valuable, contributing members of society.

The Civil Rights Act was passed in 1964, but it took years before the law really seemed to have an effect. During that time, a long-used degrading term finally became *Negro*, which became *Black*, which has become *African-American*.

Now, it's time to change the other language used in society. Labels degrade. Labels evoke negative pictures in your head. Labels don't address individuality - they lump people together! Disability labels focus on the disability - not on the person and his abilities!

Persons with disabilities want dignity, respect, and the opportunity to succeed. But those things are hard to achieve when you're saddled with a label: handicapped, disabled, crippled, autistic, blind, etc. The solution is *people first language*. What is it? It focuses on the person first, the disability last. How do you know what it is? It describes what the person *has*, not what he *is*. It's easy – just use your imagination:

Persons with disabilities... a child has cerebral palsy... my sister has a mental disability (or mental *impairment*)... my child has a developmental delay.

Many organizations are already making these changes. Others haven't, and they need a little push. Get on the bandwagon, and use your power as a parent, as a member of a support group, to ask for these changes. Write letters. Talk to people.

When you hear an incorrect description, gently correct the user and explain why it's important to use *people first language*. When it comes to basics, PFL is just good manners: treat others as you would like to be treated.

As our society's language changes, when we talk about people first, perceptions will change, and society's acceptance, inclusion, and respect for persons with disabilities will become a reality. History tells us that it takes at least one generation between the time an idea is born and the time it actually becomes incorporated into our society.

You may be advocating on behalf of one child, but your advocacy affects many, many others. Advocacy means change, and change creates tension. Don't be dismayed if you have to correct the same people many times; old habits die hard. But old habits do go away when they're replaced by good habits. Change your habits first, then work on others.

The time for people first language is *now*. Do it for one person – do it for the world!

Editor's Note: Partners Resource Network is in the process of adhering to people first language in all our publications. However, we often use names of organizations and programs that do not use PFL and our materials may include publications produced by sources that do not use this language. In these instances, we must use the official names and titles regardless.

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Appendix B

Finding Right Words is Still a Big Struggle for "Disabled People"

By Dianne B. Piastro

Q: Please! There is no such thing as handicapped parking. Why do you keep writing this? It is parking for the handicapped/disabled.

D.P., Syracuse, N.Y.

A: You're one of a growing number of people trying for grammatical precision, and I share your frustration. But, unfortunately, the term "handicapped parking" has been codified into state and federal laws since its inception. The recently implemented Americans with Disabilities Act refers to it as "accessible parking," but changing existing statutes and parking lot language will probably take a long time.

However, you've opened a Pandora's box with your assertion that I should say it's "parking for the handicapped/disabled." When individuals are referred to as "the handicapped" or "the disabled", they are defined in terms of a condition only. Today's preferred phrases are more humanizing and embrace the person by using variations of "people with disabilities" whenever possible, though "disabled persons" also is used.

Generally, people think *handicapped* and *disabled* are synonymous, but they aren't. A handicap is defined as a restriction or disadvantage in a contest.

Many people incorrectly think it comes from a time when beggars with caps in hand were the only disabled people seen in public. In fact, it comes from a 17th century English gambling game in which players thrust their hands into a cap to retrieve objects – the "winners," rather than "losers" were penalized. That is probably why the word *handicap* became associated with adding weight to superior horses to equalize a race, and with giving sports contestants advantages to equalize their chances of winning.

Later, *handicap* came to mean a barrier to performance, an obstacle in our surroundings. For example, steps are a handicap to a wheelchair user. A voice-operated telephone handicaps deaf and speech impaired persons, but a TDD equipped telephone enables them to send and receive typewritten messages; people who are blind are handicapped by a printed book, but not a recorded one. Thus, the handicap is not the inability to walk the deafness, speech impairment or blindness, it is the inaccessible, unaccommodating environment or lack of appropriate equipment.

On the other hand, the word *disable* means "to make unable; to deprive of normal strength or power." "Disability" is "that which disables, as illness." These *Webster's New Twentieth Century Dictionary* definitions hold no punches, but they do not imply that having a disability negates a person's other abilities.

When you have a disability, one or more of your functional abilities is weakened, which means you are either unable to do certain things or you do them another way. Unlike disabled cars, people are resourceful, multifaceted beings who can, and do, continue to function when they have a disability.

Carol Gill, a Chicago-based clinical psychologist who is disabled, sums it up this way: "People think it's the word itself that is difficult but it isn't. Disabled and disability are just plain speaking. We belong to one of the few groups of people in the world who can be honest about not being able to do certain things as everyone else does them. There is power in being able to say, 'So what? I can't do this particular thing, but I'm OK.' The fact that someone can't, for example, walk without assistance and gets around in a wheelchair, doesn't negate the validity of that person's value as a human being."

Nationally, disability, rather than handicap, is evolving as the word of choice. Organizations and agencies are changing their names, and legislation no longer contains the word *handicapped*. Like African-Americans, who chose to use the once pejorative word *black* as an affirmation of pride and dignity during the civil-rights era of the 1960s members of the disability movement are embracing a negative word and denying the outdated stereotypes and stigma attached to it.

But even though this trend has been gaining momentum for more than a decade, most news media coverage still perpetuates the image of disabled people as *suffering, stricken, afflicted* and *victims* who are *crippled* or *wheelchair-bound*. Being associated with the pictures those words paint isn't easy.

Such euphemisms as *physically challenged* are expressions of denial that trivialize our experience, and people with disabilities in Michigan are called handicappers. So, our movement's term for self-identification is not yet unanimous, but we're a tenacious group.

Reprinted with permission from the author from the February 2, 1992 Minneapolis *Star Tribune*.

Appendix C

ADA Requirements Fact Sheet

Employment

- Employers may not discriminate against an individual with a disability in hiring or promotion if the person is otherwise qualified for the job.
- Employers can ask about one's ability to perform a job but cannot inquire if someone has a disability or subject a person to tests that tend to screen out people with disabilities.
- Employers will need to provide "reasonable accommodation" to individuals with disabilities. This includes steps such as job restructuring and modification of equipment.
- Employers do not need to provide accommodations that impose an "undue hardship" on business operations.
- Who needs to comply:
 - All employers with twenty-five or more employees must comply, effective July 26, 1992.
 - All employers with fifteen to twenty-four employees must comply, effective July 26, 1994.

Transportation

- New public transit buses ordered after August 26, 1990, must be accessible to individuals with disabilities.
- Transit authorities must provide comparable paratransit or other special transportation services to individuals with disabilities who cannot use fixed route bus services, unless an undue burden would result.
- Existing rail systems must have one accessible car per train by July 26, 1995.
- New rail cars ordered after August 26, 1990, must be accessible.
- New bus and train stations must be accessible.
- Key stations in rapid, light, and commuter rail systems must be made accessible by July 26, 1993, with extensions up to twenty years for commuter rail (thirty years for rapid and light rail).
- All existing Amtrak stations must be accessible by July 26, 2010.

Public Accommodations

- Private entities such as restaurants, hotels, and retail stores may
-

not discriminate against individuals with disabilities, effective January 26, 1992.

- Auxiliary aids and services must be provided to individuals with vision or hearing impairments or other individuals with disabilities, unless an undue burden would result.
- Physical barriers in existing facilities must be removed, if removal is readily achievable. If not, alternate methods of providing the services must be offered, if they are readily achievable.
- All new construction and alterations of facilities must be accessible.

State and Local Government

- State and local governments may not discriminate against qualified individuals with disabilities.
- All government facilities, services, and communications must be accessible consistent with the requirements of section 504 of the Rehabilitation Act of 1973.

Telecommunications

- Companies offering telephone service to the general public must offer telephone relay services to individuals who use telecommunications devices for the deaf (TDDs) or similar devices.

This document is available in the following accessible formats: braille, large print, audio tape, electronic file on computer disk, and electronic bulletin board. Call (202) 514-6193.

For more information about the ADA, contact:

U.S. Department of Justice, Civil Rights Division, P.O. Box 66118, Washington, DC 20035-6118, (202) 514-0301 (voice), (202) 514-0381 and (202) 514-0383 (TDD)

Appendix D

What the ADA Means for People with Developmental Disabilities

By Deborah L. McFadden and Edward P. Burke

With today's signing of the landmark Americans with Disabilities Act, every man, woman, and child with a disability can now pass through once-closed doors into a bright new era of equality, independence, and freedom.

President George Bush

As we stood on the south lawn of the White House and heard the President speak these words over two years ago, we felt that a new era of opportunity and hope had dawned for people with developmental disabilities all across America. The struggle to pass the Americans with Disabilities Act (ADA) had been a long one. Strong coalitions of disabilities rights groups had been forged after decades of individual self-interest. Wary business leaders and lobbyists had been educated and negotiated with, something we in the disability rights movement were not accustomed to doing. Members of the Congress had been convinced that the passage of the ADA would be good for all Americans, not only the minority of Americans with disabilities. The challenges had been great. And, standing amidst thousands of fellow advocates as the President signed the ADA, the taste of victory was sweet: people with disabilities would now have full access to the American Dream.

Almost immediately after this historic signature ceremony at the White House, we began to hear that some disability advocates (particularly leaders in the field of mental retardation) were wondering aloud if the ADA "really" applied to their constituencies. We were somewhat surprised at this reaction from individuals whose associations had been so active in framing the Act and securing its passage. We sought to assure them that all Americans with disabilities were fully covered under the Act, including people with mental retardation and other severe disabilities. Indeed, in comparing the definition of "developmental disability" in this Act with the definition of "disability" in the ADA, we find it inconceivable that anyone who qualified as "develop mentally disabled" under the DD Act (wherein it is required that a person have "substantial functional limitations in three or more... areas of major life activity") would be considered "ineligible" for coverage under the ADA (wherein it is required that a person has an "impairment that substantially limits one or more of the major life activities").

We must all understand from the outset that people who have developmental disabilities are, in fact, covered under the Americans with Disabilities Act and have all the rights and protections guaranteed under the Act. We must also understand that the challenge of making the ADA have a significant impact on the lives of persons with developmental disabilities does mean many more years of hard work, public education, and forceful advocacy for us all.

For example, the ADA promises that, at present, employers with more than twenty-five employees cannot discriminate against qualified people with developmental disabilities in employment. This covers areas such as recruitment, hiring, job assignments, pay, layoff provisions, firing, training, promotions, benefits, and leave policy. But, to assure full benefit of this promise much must be done in expanding public attitudes about the meaning of "qualified" and in teaching and supporting people to reach their fullest ability to demonstrate their qualifications.

The ADA also promises that people with developmental disabilities will have access to nearly every conceivable public facility such as restaurants, banks, hotels, shopping centers, and offices. However, many individuals need support and opportunities to take advantage of this provision. Approaches to service delivery that institutionalize and isolate persons with developmental disabilities reflect denial by developmental disabilities specialists of access to the very opportunities society as a whole is ready to provide.

The ADA promises that people with developmental disabilities will have significantly increased access to transportation services. But such promises can be meaningfully fulfilled only if the developmental disabilities service system is willing to accept the benefits of public access over the convenience of specialized vans and buses.

Finally, the ADA promises that people with developmental disabilities that involve hearing losses or speech and language impairments will have access to mainstream telecommunications networks. But, in order for persons with developmental disabilities to benefit from such access, service providers must commit to the fullest possible development of communication abilities.

What will all of this – the letter and spirit of the ADA mean for people with developmental disabilities? First, we can foresee a day in the not-too-distant future when it will be virtually unthinkable for children with developmental disabilities to be educated anywhere but in typical neighborhood schools. Even "special transportation" will fade into obscurity as young people with disabilities travel to and attend school with their siblings and typical age peers.

Second, we see a day in which the process of moving from school to work or further education will become a natural and much smoother transition. Students with disabilities will do what their typical peers hope to do: go on for further education or get a job. "Waiting lists" for such opportunities will be unthinkable.

Third, we see a future where people with disabilities live in typical housing, not in institutions or "group homes", but in apartments and typical houses – some as renters and some as owners.

Lastly, we see a future where people with developmental disabilities will be much more involved in the social and financial lives of their communities. They will be viewed as "givers" as well as "receivers", as contributors of their time and talents to their communities. They will help to make their communities better places for everyone to live, places where it is "OK" to be different.

For all of this to happen, people with developmental disabilities and their advocates must see themselves as active players in defining what the ADA will eventually mean to our society. It is critical that people with developmental disabilities, their advocates, and professionals establish and demonstrate new and creative meanings for terms such as "qualified," "reasonable accommodation," and "readily achievable." While some have criticized the ADA as "vague" in its definitions of terms such as these, we see this as an opportunity for people with developmental disabilities and their advocates to test the limits of creativity in developing new avenues of opportunity for the full participation of people with developmental disabilities in society.

Being creative does not necessarily mean being expensive for businesses and communities. Many of the "technologies" that can help people with severe disabilities function and flourish in the workplace have already been "invented": job coaches, personal care attendants, augmentative communication aids, and the like. Many of these supports are or can be funded by governmentally-financed programs. While we hope that in the future more employers will provide assistance to people with developmental disabilities directly (indeed, some already are), it is the case that many of the costs associated with "reasonable accommodation" are already paid for, or could be paid for, under other programs. The challenge to advocates is to both identify and further develop these technologies and supports and to ensure that they are available to people with developmental disabilities, their (potential) employers, and communities. The result will be that when discussions arise regarding who is "qualified" or what constitutes "reasonable accommodation," people with developmental disabilities, their families, and other advocates can make it easy for others to say *Yes*.

Staff members of the Administration on Developmental Disabilities (ADD) are continually seeking ways to increase the independence, productivity, and community inclusion of people with developmental disabilities. They see in the ADA an opportunity to create vastly improved futures for the people they serve. ADD has invested resources in making the promise of the ADA a reality for people with developmental disabilities across America through innovative projects funded by the Developmental Disabilities Councils in every state, through the pioneering work of the Uni-

versity Affiliated Programs in discovering better forms of accommodation, and through the efforts of the Protection and Advocacy Systems to promote and safeguard the rights of persons with developmental disabilities.

It is our belief that this vital work must continue. We trust that those who have fought for so long to see people with developmental disabilities treated with respect in the light of equality will persevere along with us. Together, we will continue to discover creative ways to ensure that every man, woman, and child with a developmental disability in America will be able, in the President's words, "to pass through once-closed doors into a bright new era of equality, independence and freedom."

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Appendix E

Section 504 Fact Sheet

What is it?

Section 504 is a section of the Rehabilitation Act of 1973 which protects the rights of persons with disabilities. It prohibits agencies or organization which receive federal funds from discriminating against otherwise qualified individuals solely on the basis of disability.

What is a disability under 504?

An individual is determined to have a disability if she/he:

- 1 Has a physical or mental impairment which substantially limits one or more major life activities (walking, seeing, hearing, speaking, breathing, learning, working, caring for oneself, performing manual tasks);
- 2 has a record of such impairment; *or*
- 3 is regarded as having such an impairment.

This can mean that a school-age child who has an attention deficit disorder and does not qualify for special education services may still be entitled to accommodation in regular education under Section 504.

What are "reasonable accommodations" under 504?

Accommodations must achieve meaningful equal opportunity, must consider the functional limitations of the person and alternative methods of performance. Some examples could be the following: modified testing, preferential seating, taped textbooks, readers, tailoring homework assignments, etc.

Are evaluations and IEP required?

A district must evaluate "any person who, because of handicap, needs or is believed to need special education or related services". Evaluation is also required prior to a significant change in placement.

A written plan describing placement and services must be developed. A formal IEP is not required, but decisions will be made by a group of persons. Placement decisions must be based on information from varied sources and must be documented. All information must be considered. Decisions must be made by a group of persons who are knowledgeable about the child, the meaning of the data, and placement options.

What are the responsibilities of schools?

Schools must provide assurance of non-discrimination, designate an employee to ensure compliance, provide grievance proce-

dures, identify and locate all qualified children with disabilities who are receiving public education, provide notice of district's 504 responsibilities and procedural safeguards. The procedural safeguards are as follows:

- 1 The right to written notice
- 2 The right to review records
- 3 The right to an impartial hearing

What if there appears to be a violation?

The Office of Civil Rights investigates Section 504 complaints. Minnesota is in Region V, 300 Wacker Drive, Chicago, Illinois 60606; telephone 312/353-2520.

Appendix F

Delegation & Nursing Practice

By Mary Tyrrell, Assistant Director,
Nursing Assistant Program, Minnesota Board of Nursing

The primary responsibility of the Minnesota Board of Nursing is to protect the public health, safety, and welfare through the regulation of nursing practice. Registered nurses and licensed practical nurses in Minnesota are granted licenses to practice nursing in Minnesota under the provisions of the Nurse Practice Act. This act establishes the parameters of practice within nursing. The professional nurse is authorized to delegate independent nursing functions and delegated medical functions to other nursing personnel. The licensed practical nurse is not given this authorization in the Nurse Practice Act.

Familiarity with delegation is especially important for the professional nurse in long term care who delegates a variety of tasks to the licensed practical nurse and the nursing assistant. Even if the assistant has a special title such as trained medication aide (TMA), home health aide (HHA), personal care assistant (PCA), or human services technician (HST), the decision to delegate nursing care rests with the registered nurse. The delegating nurse retains accountability for the act delegated to another person and has the responsibility to determine that the delegatee is competent to perform the delegated act. Furthermore, the delegating nurse must provide appropriate supervision.

The decision of whether or not to delegate to other nursing personnel rests with the professional nurse. Both the status of the resident or client and the knowledge and skill of the person receiving the delegation (the "delegatee") must be considered. Thus, the delegator has the responsibility to make a proper act of delegation by giving clear, specific directions to a person who can perform them safely and competently. And the delegatee has the responsibility of carrying out the delegated act or function correctly. Good communication between the giver and recipient is necessary so that any ambiguity in instruction or lack of ability can be addressed.

For example, the charge nurse in a facility may recognize that TMA appears overwhelmed with a work assignment. The TMA may be willing to take on the task, but it is the nurse's responsibility to verify that the work will be done safely. If the TMA makes a mistake, the nurse is responsible for the TMA's performance and is responsible for delegating properly.

Long-term care is an essential and creative component in

today's continuum of health care. The availability of staff is a critical issue, and delegation can be very cost-effective. However, safety of the client/resident must remain the primary issue.

Reprinted with permission from *OBRA Implementation Newsletter*, June 1990, #6.

Appendix G

The Minnesota Nurse Practice Act

Chapter 148 – Public Health Occupations, Licensing Registered Nurses and Licensed Practical Nurses

148.171 – Definitions

Sections 148.171 to 148.285 shall be referred to as the Minnesota nurse practice act. As used in sections 148.171 to 148.285:

- 1 "Board" means the Minnesota board of nursing.
- 2 "Registered nurse," abbreviated R.N., means an individual licensed by the board to practice professional nursing.
- 3 The practice of professional nursing means the performance for compensation or personal profit of the professional interpersonal service of: a) providing a nursing assessment of the actual or potential health needs of individuals, families, or communities; b) providing nursing care supportive to or restorative of life by functions such as skilled ministrations of nursing care, supervising and teaching nursing personnel, health teaching and counseling, case finding, and referral to other health resources; and c) evaluating these actions.

The practice of professional nursing includes both independent nursing functions and delegated medical functions which may be performed in collaboration with other health team members, or may be delegated by the professional nurse to other nursing personnel. Independent nursing function may also be performed autonomously. The practice of professional nursing requires that level of special education, knowledge, and skill ordinarily expected of an individual who has completed an approved professional nursing education program as described in section 148.211, subdivision 1.

- 4 "Licensed practical nurse," abbreviated L.P.N., means an individual licensed by the board to practice practical nursing.
- 5 The practice of practical nursing means the performance for compensation or personal profit of any of those services in observing and caring for the ill, injured, or infirm, in applying counsel and procedure to safeguard life and health, in administering medication and treatment prescribed by a licensed health professional, which are commonly performed by licensed practical nurses and which require specialized knowledge and skill such as are taught or acquired in an approved school of practical nursing, but which do not require the specialized education, knowledge, and skill of a registered nurse.

- 6 "Nurse" means registered nurse and licensed practical nurse unless the context clearly refers to only one category.
- 7 "Nursing assistant" means an individual providing nursing or nursing-related services that do not require the specialized knowledge and skill of a nurse, at the direction of a nurse, but does not include a licensed health professional or an individual who volunteers to provide such services without monetary compensation.
- 8 "Public health nurse" means a registered nurse who meets the voluntary registration requirements established by rule.

HIST: 1945 c 242 s 1; 1955 c 34 s 1; 1959 c 140 s 1; 1974 c 554 s 1; 1988 c 440 s 1; 1989 c 194 s 3; 1990 c 483 s 1

148.181 Board of Nursing Membership; Vacancies; Disclosure

Subd. 1 – Membership: The board of nursing consists of sixteen members appointed by the governor, each of whom must be a resident of this state. Eight members must be registered nurses, each of whom must have graduated from an approved school of nursing, must be licensed and currently registered as a registered nurse in this state, and must have had at least five years experience in nursing practice, nursing administration, or nursing education immediately preceding appointment. One of the eight must have had at least two years executive or teaching experience in a baccalaureate degree nursing program approved by the board under section 148.251 during the five years immediately preceding appointment, one of the eight must have had at least two years executive or teaching experience in an associate degree nursing program approved by the board under section 148.251 during the five years immediately preceding appointment, one of the eight must be practicing professional nursing in a nursing home at the time of appointment, one of the eight must have had at least two years executive or teaching experience in a practical nursing program approved by the board under section 148.251 during the five years immediately preceding appointment, and one of the eight must have national certification as a registered nurse anesthetist, nurse practitioner, nurse midwife, or clinical nurse specialist. Four of the eight must have had at least five years of experience in nursing practice or nursing administration immediately preceding appointment. Four members must be licensed practical nurses, each of whom must have graduated from an approved school of nursing, must be licensed and currently registered as a licensed practical nurse in this state, and must have had at least five years experience in nursing practice immediately preceding appointment. The remaining four members must be public members as defined by section 214.02.

A member may be reappointed but may not serve more than two full terms consecutively. The governor shall attempt to make

appointments to the board that reflect the geography of the state. Board members who are nurses should reflect the broad mix of practice types and sites of nurses practicing in Minnesota.

Membership terms, compensation of members, removal of members, the filling of membership vacancies, and fiscal year and reporting requirements are as provided in sections 214.07 to 214.09. Any nurse on the board who during incumbency permanently ceases to be actively engaged in the practice of nursing or otherwise becomes disqualified for board membership is automatically removed, and the governor shall fill the vacancy. The provision of staff, administrative services, and office space; the review and processing of complaints; the setting of board fees; and other provisions relating to board operations are as provided in sections 148.171 to 148.285 and chapter 214. Each member of the board shall file with the secretary of state the constitutional oath of office before beginning the term of office.

Subd. 2 – Vacancies: On expiration of the term of a member who is a registered nurse, the governor may appoint a registered nurse from a list of members submitted by professional nursing groups. Likewise on expiration of the term of a member who is a licensed practical nurse, the governor may appoint a licensed practical nurse from a list of members submitted by licensed practical nursing groups. These lists should contain names of persons in number at least twice the number of places to be filled. Vacancies occurring on the board, when the member is a registered nurse or a licensed practical nurse, may be filled for the unexpired terms by appointments to be made by the governor from nominations submitted by nursing groups in the manner aforesaid or from other recommendations. Members shall hold office until a successor is appointed and qualified.

Subd. 3: Repealed, 1975 c 136 s 77

Subd. 3 – Disclosure: A disciplinary hearing must be closed to the public. Upon application of a party in a proceeding before the board under section 148.261, the board shall produce and permit the inspection and copying, by or on behalf of the moving party, of any designated documents or papers relevant to the proceedings, in accordance with rule 34 of the Minnesota rules of civil procedure.

HIST: 1945 c 242 s 2; 1955 c 34 638 s 14; 1975 c 136 s 10; 1975 c 360 s 1,2; 1976 c 222 s 50; 1976 c 239 s 55; 1981 c 94 s 1; 1986 c 444; 1989 c 194 s 4; 1993 c 88 s 1,2; 1993 c 105 s 1; 1993 c 366 s 1

148.191 Officers; Staff; Powers

Subd. 1 – Officers; Staff: The board shall elect from its members a president, a vice-president, and a secretary-treasurer who shall each serve for one year or until a successor is elected and qualifies. The board shall appoint and employ an executive director and may employ such persons as may be necessary to carry on its work. A majority of the board, including one officer, shall constitute a quorum at any meeting.

Subd. 2 – Powers:

A The board is authorized to adopt and, from time to time, revise rules not inconsistent with the law, as may be necessary to enable it to carry into effect the provisions of sections 148.171 to 148.285. The board shall prescribe by rule curricula and standards for schools and courses preparing persons for licensure under sections 148.171 to 148.285. It shall conduct or provide for surveys of such schools and courses at such times as it may deem necessary. It shall approve such schools and courses as meet the requirements of sections 148.171 to 148.285 and board rules. It shall examine, license, and renew the license of duly qualified applicants. It shall hold examinations at least once in each year at such time and place as it may determine. It shall by rule adopt, evaluate, and periodically revise, as necessary, requirements for licensure and for registration and renewal of registration as defined in section 148.231. It shall cause the prosecution of all persons violating sections 148.171 to 148.285 and have power to incur such necessary expense therefor. It shall register public health nurses who meet educational and other requirements established by the board by rule, including payment of a fee. Prior to the adoption of rules, the board shall use the same procedures used by the department of health to certify public health nurses. It shall have power to issue subpoenas, and to compel the attendance of witnesses and the production of all necessary documents and other evidentiary material. Any board member may administer oaths to witnesses, or take their affirmation. It shall keep a record of all its proceedings.

B The board shall have access to hospital, nursing home, and other medical records of a patient cared for by a nurse under review. If the board does not have a written consent from a patient permitting access to the patient's records, the nurse or facility shall delete any data in the record that identifies the patient before providing it to the board. The board shall have access to such other records as reasonably requested by the board to assist the board in its investigation. Nothing herein may be construed to allow access to any records protected by section 145.64. The board shall maintain any records obtained pursuant to this paragraph as investigative data under chapter 13.

Subd. 3: Repealed, 1989 c 194 s 22

HIST: 1945 c 242 s 3; 1955 c 847 s 13; 1975 c 136 s 12; 1975 c 240 s 1; 1975 c 360 s 3; 1976 c 222 s 51; 1983 c 260 s 36; 1986 c 444; 1989 c 194 s 5

148.211 – Licensing

Subd. 1 – Licensure by Examination: An applicant for a license to practice as a registered nurse or licensed practical nurse shall apply to the board for a license by examination on forms prescribed by the board and pay a fee in an amount determined by rule. An applicant applying for reexamination shall pay a fee in an amount determined by rule. In no case may fees be refunded.

Before being scheduled for examination, the applicant shall provide written evidence verified by oath that the applicant 1) has not engaged in conduct warranting disciplinary action as set forth in section 148.261; 2) meets secondary education requirements as determined by the board and other preliminary qualification requirements the board may prescribe by rule; and 3) has completed a course of study in a nursing program approved by the board, another United States nursing board, or a Canadian province. An applicant who graduates from a nursing program in another country, except Canada, must also successfully complete the Commission on Graduates of Foreign Nursing Schools Qualifying Examination. The nursing program must be approved for the preparation of applicants for the type of license for which the application has been submitted.

The applicant must pass a written examination in the subjects the board may determine. Written examination includes both paper and pencil examinations and examinations administered with a computer and related technology. Each written examination may be supplemented by an oral or practical examination. An applicant failing to pass the examination may apply for reexamination.

Upon submission by the applicant of an affidavit of graduation or transcript from an approved nursing program as well as proof that the applicant has passed the examination, paid the required fees, and met all other requirements stated in this subdivision, the board shall issue a license to the applicant. The board may issue a license with conditions and limitations if it considers it necessary to protect the public.

Subd. 2 – Licensure by Endorsement: The board shall issue a license to practice professional nursing or practical nursing without examination to an applicant who has been duly licensed or registered as a nurse under the laws of another state, territory, or country, if in the opinion of the board the applicant has the qualifications equivalent to the qualifications required in this state as stated in subdivision 1, all other laws not inconsistent with this section, and rules promulgated by the board.

Subd. 3: Repealed, 1976 c 222 s 209

Subd. 4 – Education Waived: A person who has been licensed as a licensed practical nurse in another state, who has passed a licensing examination acceptable to the board, and who has had 24 months of experience as a licensed practical nurse in the five years prior to applying for a license is not required to meet any additional educational requirements.

Subd. 5 – Denial of License: Refusal of an applicant to supply information necessary to determine the applicant's qualifications, failure to demonstrate qualifications, or failure to satisfy the requirements for a license contained in this section or rules of the board may result in denial of a license. The burden of proof is upon the applicant to demonstrate the qualifications and satisfac-

tion of the requirements.

HIST: 1945 c 242 s 5; 1955 c 34 s 4; 1961 c 56 s 1; 1967 c 68 s 1; 1969 c 53 s 1; 1975 c 360 s 4,5; 1976 c 222 s 52,53; 1981 c 94 s 2; 1986 c 444; 1989 c 194 s 6; 1993 c 88 s 3

148.212 – Temporary Permit

Upon receipt of the applicable licensure or re-registration fee and permit fee, and in accordance with rules of the board, the board may issue a nonrenewable temporary permit to practice professional or practical nursing to an applicant for licensure or reregistration who is not the subject of a pending investigation or disciplinary action, nor disqualified for any other reason, under the following circumstances:

- A The applicant for licensure by examination under section 148.211, subdivision 1, has graduated from an approved nursing program within the sixty days preceding board receipt of an affidavit of graduation or transcript and has been authorized by the board to write the licensure examination for the first time in the United States. The permit holder must practice professional or practical nursing under the direct supervision of a registered nurse. The permit is valid from the date of issue until the date the board takes action on the application or for sixty days, whichever occurs first.
- B The applicant for licensure by endorsement under section 148.211, subdivision 2, is currently licensed to practice professional or practical nursing in another state, territory, or Canadian province. The permit is valid from submission of a proper request until the date of board action on the application.
- C The applicant for licensure by endorsement under section 148.211, subdivision 2, or for reregistration under section 148.231, subdivision 5, is currently registered in a formal, structured refresher course or its equivalent for nurses that includes clinical practice.

HIST: 1989 c 194 s 7; 1993 c 88 s 4

148.231 – Registration; Failure to Register; Re-registration; Verification

Subd. 1 – Registration: Every person licensed to practice professional or practical nursing must maintain with the board a current registration for practice as a registered nurse or licensed practical nurse which must be renewed at regular intervals established by the board by rule. No certificate of registration shall be issued by the board to a nurse until the nurse has submitted satisfactory evidence of compliance with the procedures and minimum requirements established by the board.

The fee for periodic registration for practice as a nurse shall be determined by the board by rule. A penalty fee shall be added for any application received after the required date as specified by

the board by rule. Upon receipt of the application and the required fees, the board shall verify the application and the evidence of completion of continuing education requirements in effect, and thereupon issue to the nurse a certificate of registration for the next renewal period.

Subd. 2: Repealed, 1981 c 94 s 12

Subd. 3: Repealed, 1976 c 222 s 209

Subd. 4 – Failure to Register: Any person licensed under the provisions of sections 148.171 to 148.285 who fails to register within the required period shall not be entitled to practice nursing in this state as a registered nurse or licensed practical nurse.

Subd. 5 – Re-registration: A person whose registration has lapsed desiring to resume practice shall make application for re-registration, submit satisfactory evidence of compliance with the procedures and requirements established by the board, and pay the registration fee for the current period to the board. Thereupon, the registration certificate shall be issued to the person who shall immediately be placed on the practicing list as a registered nurse or licensed practical nurse.

Subd. 6 – Verification: A person licensed under the provisions of sections 148.171 to 148.285 who requests the board to verify a Minnesota license to another state, territory, or country or to an agency, facility, school, or institution shall pay a fee to the board for each verification.

HIST: 1945 c 242 s 7; 1947 c 286 s 1; 1955 c 34 s 5; 1961 c 8 s 2; 1967 c 68 s 2; 1969 c 53 s 2,3; 1971 c 131 s 1; 1975 c 240 s 2; 1975 c 360 s 6,7; 1976 c 149 s 30; 1981 c 94 s 3-6; 1986 c 444; 1989 c 194 s 8

148.232 – Registration of Public Health Nurses.

A public health nurse certified for public health duties by the commissioner of health under section 145A.06, subdivision 3, or previous authority must be deemed to be registered as a public health nurse under the provisions of sections 148.171 to 148.285.
HIST: 1989 c 194 s 9

148.235 – Prescribing Drugs and Therapeutic Devices.

Subd. 1 – Nurse-midwives: A registered nurse who has graduated from a program of study designed to prepare registered nurses for advanced practice as nurse-midwives and who is certified through the national professional nursing organization for nurse-midwives may prescribe and administer drugs and therapeutic devices within practice as a nurse-midwife.

Subd. 2 – Nurse Practitioners: A registered nurse who 1) has graduated from a program of study designed to prepare registered nurses for advanced practice as nurse practitioners; 2) is certified through a national professional nursing organization which certifies nurse practitioners and is included in the list of professional nursing organizations adopted by the board under section 62A.15, subdivision 3a; and 3) has a written agreement with a physician

based on standards established by the Minnesota nurses association and the Minnesota medical association that defines the delegated responsibilities related to the prescription of drugs and therapeutic devices, may prescribe and administer drugs and therapeutic devices within the scope of the written agreement and within practice as a nurse practitioner.

Subd. 3 – Dispensing Authority: An advanced practice nurse who is authorized under this section to prescribe drugs is authorized to dispense drugs subject to the same requirements established for the prescribing of drugs. This authority to dispense extends only to those drugs described in the written agreement entered into under this section. The authority to dispense includes, but is not limited to, the authority to receive and dispense sample drugs.

Subd. 4 – Clinical Specialists in Psychiatric and Mental Health Nursing: A registered nurse who 1) has a masters degree; 2) is certified through a national professional nursing organization which certifies clinical specialists in psychiatric and mental health nursing and is included in the list of professional nursing organizations adopted by the board under section 62A.15, subdivision 3a; 3) has successfully completed no less than thirty hours of formal study in the prescribing of psychotropic medications and medications to treat their side effects which included instruction in health assessment, psychotropic classifications, psychopharmacology, indications, dosages, contraindications, side effects, and evidence of application; and 4) has a written agreement with a psychiatrist based on standards established by the Minnesota nurses association and the Minnesota psychiatric association that specifies and defines the delegated responsibilities related to the prescription of drugs in relationship to the diagnosis, may prescribe and administer drugs used to treat psychiatric and behavioral disorders and the side effects of those drugs within the scope of the written agreement and within practice as a clinical specialist in psychiatric and mental health nursing.

Nothing in this subdivision removes or limits the legal professional liability of the treating psychiatrist, clinical nurse specialist, mental health clinic, or hospital for the prescription and administration of drugs by a clinical specialist in accordance with this subdivision.

Subd. 5 – Rules

A The board shall promulgate rules to provide for the following:

- 1 A system of identifying advanced practice nurses eligible to prescribe drugs as authorized under this section;
- 2 A system of transmitting to pharmacists the identity of advanced practice nurses eligible to prescribe drugs; and
- 3 A fee to nurse practitioners and certified clinical specialists in psychiatric and mental health nursing who seek prescribing authority.

B The repeal of subdivision 2, paragraph (b), does not automatically repeal rules adopted under that paragraph.
HIST: 1990 c 483 s 2; 1993 c 337 s 10; 1994 c 389 s 2; 1994 c 470 s 1-3

148.236 – Funding for Nursing Grants

Subd. 1 – Registered Nurse Funding:

A The nursing grant program shall be funded by a \$5.50 fee on each registration renewal of registered nurses as provided under section 148.231, unless the applicant specifically indicates on the renewal form that the applicant does not wish to participate in the funding of this program. The board of nursing shall transfer all money received under this subdivision, less an amount sufficient to pay the costs of administering the program not to exceed twelve percent of the fee collected under this subdivision, to the higher education coordinating board on a quarterly basis. This money is available until expended by the higher education coordinating board. By January 1, 1991, and each subsequent year, the board of nursing shall provide an estimate to the higher education coordinating board of the amount of money that may be available each year based on the number of anticipated registration renewals in that year.

B Notwithstanding paragraph "A", up to the first \$11,000 of fees collected under this subdivision may be used to program the board of nursing's computer system for purposes of administering this section.

Subd. 2 – Licensed Practical Nurse Funding:

A The nursing grant program shall be funded by a \$5.50 fee on each registration renewal of licensed practical nurses as provided under section 148.231, unless the applicant specifically indicates on the renewal form that the applicant does not wish to participate in the funding of this program. The board of nursing shall transfer all money received under this subdivision, less an amount sufficient to pay the costs of administering the program not to exceed twelve percent of the fee collected under this subdivision, to the higher education coordinating board on a quarterly basis. This money is available until expended by the higher education coordinating board. By January 1, 1991, and each subsequent year, the board of nursing shall provide an estimate to the higher education coordinating board of the amount of money that may be available each year based on the number of anticipated registration renewals in that year.

B Notwithstanding paragraph "A", up to the first \$6,000 of fees collected under this subdivision may be used to program the board of nursing's computer system for purposes of administering this section.

HIST: 1990 c 568 art 2 s 100

148.241 – Expenses

Subd. 1 – Appropriation: The expenses of administering sections

148.171 to 148.285 shall be paid from the appropriation made to the Minnesota board of nursing.

Subd. 2 – Expenditure: All amounts appropriated to the board shall be held subject to the order of the board to be used only for the purpose of meeting necessary expenses incurred in the performance of the purposes of sections 148.171 to 148.285, and the duties imposed thereby as well as the promotion of nursing education and standards of nursing care in this state.

HIST: 1945 c 242 s 8; 1955 c 34 s 3; 1973 c 638 s 16; 1976 c 222 s 54; 1989 c 194 s 10

148.251 – Nursing Program

Subd. 1 – Initial Approval: An institution desiring to conduct a nursing program shall apply to the board and submit evidence that:

- 1 It is prepared to provide a program of theory and practice in professional or practical nursing that meets the program approval standards adopted by the board. Instruction and required experience may be obtained in one or more institutions or agencies outside the applying institution as long as the nursing program retains accountability for all clinical and nonclinical teaching.
- 2 It is prepared to meet other standards established by law and by the board.

Subd. 2: Repealed, 1989 c 194 s 22

Subd. 3 – Continuing Approval: From time to time as deemed necessary by the board, it shall be the duty of the board, through its representatives, to survey all nursing programs in the state. If the results of the survey show that a nursing program meets all board rules, the board shall continue approval of the nursing program.

Subd. 4 – Loss of Approval: If the board determines that an approved nursing program is not maintaining the standards required by the statutes and board rules, notice thereof in writing specifying the defect shall be given to the program. If a program fails to correct these conditions to the satisfaction of the board within a reasonable time, approval of the program shall be revoked and the program shall be removed from the list of approved nursing programs.

Subd. 5 – Reinstatement of Approval: The board shall reinstate approval of a nursing program upon submission of satisfactory evidence that its program of theory and practice meets the standards required by statutes and board rules.

Subd. 6 – Advanced Standing: Associate degree nursing programs approved or seeking to be approved by the board shall provide for advanced standing for licensed practical nurses in recognition of their nursing education and experience.

HIST: 1945 c 242 s 9; 1961 c 56 s 2; 1975 c 360 s 8; 1981 c 94 s 7; 1989 c 194 s 11

148.261 – Grounds for Disciplinary Action

Subd. 1 – Grounds Listed: The board may deny, revoke, suspend, limit, or condition the license and registration of any person to practice professional or practical nursing under sections 148.171 to 148.285, or to otherwise discipline a licensee or applicant as described in section 148.262. The following are grounds for disciplinary action:

- 1 Failure to demonstrate the qualifications or satisfy the requirements for a license contained in sections 148.171 to 148.285 or rules of the board. In the case of a person applying for a license, the burden of proof is upon the applicant to demonstrate the qualifications or satisfaction of the requirements.
- 2 Employing fraud or deceit in procuring or attempting procure a permit, license, or registration certificate to practice professional or practical nursing or attempting to subvert the licensing examination process. Conduct that subverts or attempts to subvert the licensing examination process includes, but is not limited to:
 - i conduct that violates the security of the examination materials, such as removing examination materials from the examination room or having unauthorized possession of any portion of a future, current, or previously administered licensing examination;
 - ii conduct that violates the standard of test administration, such as communicating with another examinee during administration of the examination, copying another examinee's answers, permitting another examinee to copy one's answers, or possessing unauthorized materials; or
 - iii impersonating an examinee or permitting an impersonator to take the examination on one's own behalf.
- 3 Conviction during the previous five years of a felony or gross misdemeanor reasonably related to the practice of professional or practical nursing. Conviction as used in this subdivision includes a conviction of an offense that if committed in this state would be considered a felony or gross misdemeanor without regard to its designation elsewhere, or a criminal proceeding where a finding or verdict of guilt is made or returned but the adjudication of guilt is either withheld or not entered.
- 4 Revocation, suspension, limitation, conditioning, or other disciplinary action against the person's professional or practical nursing license in another state, territory, or country; failure to report to the board that charges regarding the person's nursing license are pending in another state, territory, or country; or having been refused a license by another state, territory, or country.
- 5 Failure to or inability to perform professional or practical

nursing as defined in section 148.171, paragraph "3" or "5", with reasonable skill and safety, including failure of a registered nurse to supervise or a licensed practical nurse to monitor adequately the performance of acts by any person working at the nurse's direction.

- 6 Engaging in unprofessional conduct, including, but not limited to, a departure from or failure to conform to board rules of professional or practical nursing practice that interpret the statutory definition of professional or practical nursing as well as provide criteria for violations of the statutes, or, if no rule exists, to the minimal standards of acceptable and prevailing professional or practical nursing practice, or any nursing practice that may create unnecessary danger to a patient's life, health, or safety. Actual injury a patient need not be established under this clause.
 - 7 Delegating or accepting the delegation of a nursing function or a prescribed health care function when the delegation or acceptance could reasonably be expected to result in unsafe or ineffective patient care.
 - 8 Actual or potential inability to practice nursing with reasonable skill and safety to patients by reason of illness, use of alcohol, drugs, chemicals, or any other material, or as a result of any mental or physical condition.
 - 9 Adjudication as mentally incompetent, mentally ill, a chemically dependent person, or a person dangerous to the public by a court of competent jurisdiction, within or without this state.
 - 10 Engaging in any unethical conduct, including, but not limited to, conduct likely to deceive, defraud, or harm the public, or demonstrating a willful or careless disregard for the health, welfare, or safety of a patient. Actual injury need not be established under this clause.
 - 11 Engaging in conduct with a patient that is sexual or may reasonably be interpreted by the patient as sexual, or in any verbal behavior that is seductive or sexually demeaning to a patient, or engaging in sexual exploitation of a patient or former patient.
 - 12 Obtaining money, property, or services from a patient, other than reasonable fees for services provided to the patient, through the use of undue influence, harassment, duress, deception, or fraud.
 - 13 Revealing a privileged communication from or relating to a patient except when otherwise required or permitted by law.
 - 14 Engaging in abusive or fraudulent billing practices, including violations of federal Medicare and Medicaid laws or state medical assistance laws.
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- 15 Improper management of patient records, including failure to maintain adequate patient records, to comply with a patient's request made pursuant to section 144.335, or to furnish a patient record or report required by law.
- 16 Knowingly aiding, assisting, advising, or allowing an unlicensed person to engage in the unlawful practice of professional or practical nursing.
- 17 Violating a rule adopted by the board, an order of the board, or a state or federal law relating to the practice of professional or practical nursing, or a state or federal narcotics or controlled substance law.
- 18 Knowingly providing false or misleading information that is directly related to the care of that patient unless done for an accepted therapeutic purpose such as the administration of a placebo.
- 19 Aiding suicide or aiding attempted suicide in violation of section 609.215 as established by any of the following:
 - i a copy of the record of criminal conviction or plea of guilty for a felony in violation of section 609.215, subdivision 1 or 2;
 - ii a copy of the record of a judgment of contempt of court for violating an injunction issued under section 609.215, subd. 4;
 - iii a copy of the record of a judgment assessing damages under section 609.215, subdivision 5; *or*
 - iv a finding by the board that the person violated section 609.215, subdivision 1 or 2. The board shall investigate any complaint of a violation of section 609.215, subdivision 1 or 2.
- 20 Practicing outside the scope of practice authorized by section 148.171, paragraph "3" or "5".
- 21 Making a false statement or knowingly providing false information to the board, failing to make reports as required by section 148.263, or failing to cooperate with an investigation of the board as required by section 148.265.
- 22 Engaging in false, fraudulent, deceptive, or misleading advertising.

Subd. 2: Repealed, 1976 c 222 s 209

Subd. 3: Repealed, 1989 c 194 s 22

Subd. 4 – Evidence: In disciplinary actions alleging a violation of subdivision 1, clause "3" or "4", a copy of the judgment or proceeding under the seal of the court administrator or of the administrative agency that entered the same shall be admissible into evidence without further authentication and shall constitute prima facie evidence of the violation concerned.

Subd. 5 – Examination; Access to Medical Data: The board may take the following actions if it has probable cause to believe that grounds for disciplinary action exist under subdivision 1, clause "8" or "9":

A It may direct the applicant or nurse to submit to a mental or physical examination or chemical dependency evaluation. For the purpose of this subdivision, when a nurse licensed under sections 148.171 to 148.285 is directed in writing by the board to submit to a mental or physical examination or chemical dependency evaluation, that person is considered to have consented and to have waived all objections to admissibility on the grounds of privilege. Failure of the applicant or nurse to submit to an examination when directed constitutes an admission of the allegations against the applicant or nurse, unless the failure was due to circumstances beyond the person's control, and the board may enter a default and final order without taking testimony or allowing evidence to be presented. A nurse affected under this paragraph shall, at reasonable intervals, be given an opportunity to demonstrate that the competent practice of professional or practical nursing can be resumed with reasonable skill and safety to patients. Neither the record of proceedings nor the orders entered by the board in a proceeding under this paragraph, may be used against a nurse in any other proceeding.

B It may, notwithstanding sections 13.42, 144.651, 595.02, or any other law limiting access to medical or other health data, obtain medical data and health records relating to a registered nurse, licensed practical nurse, or applicant for a license without that person's consent. The medical data may be requested from a provider, as defined in section 144.335, subdivision 1, paragraph (b), an insurance company, or a government agency, including the department of human services. A provider, insurance company, or government agency shall comply with any written request of the board under this subdivision and is not liable in any action for damages for releasing the data requested by the board if the data are released pursuant to a written request under this subdivision unless the information is false and the provider giving the information knew, or had reason to believe, the information was false. Information obtained under this subdivision is classified as private data on individuals as defined in section 13.02.

HIST: 1945 c 242 s 10; 1975 c 360 s 9; 1976 c 222 s 55; 1986 c 444; 1989 c 194 s 12; 1992 c 464 art 1 s 56; 1992 c 559 art 1 s 4; 1992 c 577 s 3; 1993 c 88 s 5

148.262 – Forms of Disciplinary Action; Automatic Suspension; Temporary Suspension; Reissuance

Subd. 1 – Forms of Disciplinary Action: When the board finds that grounds for disciplinary action exist under section 148.261, subdivision 1, it may take one or more of the following actions:

- 1 Deny the license, registration, or registration renewal;
- 2 Revoke the license;
- 3 Suspend the license;
- 4 Impose limitations on the nurse's practice of professional or prac-

tical nursing including, but not limited to, limitation of scope of practice or the requirement of practice under supervision;

- 5 Impose conditions on the retention of the license including, but not limited to, the imposition of retraining or rehabilitation requirements or the conditioning of continued practice on demonstration of knowledge or skills by appropriate examination, monitoring, or other review;
- 6 Impose a civil penalty not exceeding \$10,000 for each separate violation, the amount of the civil penalty to be fixed as to deprive the nurse of any economic advantage gained by reason of the violation charged, to reimburse the board for the cost of counsel, investigation, and proceeding, and to discourage repeated violations;
- 7 Order the nurse to provide unremunerated service;
- 8 Censure or reprimand the nurse; or
- 9 Any other action justified by the facts in the case.

Subd. 2 – Automatic Suspension: Unless the board orders otherwise, a license to practice professional or practical nursing is automatically suspended if:

- 1 A guardian of a nurse is appointed by order of a court under sections 525.54 to 525.61;
- 2 The nurse is committed by order of a court under chapter 253b; *or*
- 3 The nurse is determined to be mentally incompetent, mentally ill, chemically dependent, or a person dangerous to the public by a court of competent jurisdiction within or without this state.

The license remains suspended until the nurse is restored to capacity by a court and, upon petition by the nurse, the suspension is terminated by the board after a hearing or upon agreement between the board and the nurse.

Subd. 3 – Temporary Suspension of License: In addition to any other remedy provided by law, the board may, through its designated board member under section 214.10, subdivision 2, temporarily suspend the license of a nurse without a hearing if the board finds that there is probable cause to believe the nurse has violated a statute or rule the board is empowered to enforce and continued practice by the nurse would create a serious risk of harm to others. The suspension shall take effect upon written notice to the nurse, served by first-class mail, specifying the statute or rule violated. The suspension shall remain in effect until the board issues a temporary stay of suspension or a final order in the matter after a hearing or upon agreement between the board and the nurse. At the time it issues the suspension notice, the board shall schedule a disciplinary hearing to be held under the administrative procedure act. The nurse shall be provided with at least twenty days' notice of any hearing held under this subdivision. The hearing

shall be scheduled to begin no later than thirty days after the issuance of the suspension order.

Subd. 4 – Reissuance: The board may reinstate and reissue a license or registration certificate to practice professional or practical nursing, but as a condition may impose any disciplinary or corrective measure that it might originally have imposed. Any person whose license or registration has been revoked, suspended, or limited may have the license reinstated and a new registration issued when, in the discretion of the board, the action is warranted, provided that the person shall be required by the board to pay the costs of the proceedings resulting in the revocation, suspension, or limitation of the license or registration certificate and reinstatement of the license or registration certificate, and to pay the fee for the current registration period. The cost of proceedings shall include, but not be limited to, the cost paid by the board to the office of administration hearings and the office of the attorney general for legal and investigative services, the costs of a court reporter and witnesses, reproduction of records, board staff time, travel, and expenses, and board members' per diem reimbursements, travel costs, and expenses.

HIST: 1989 c 194 s 13; 1Sp1994 c 1 art 2 s 8

148.263 – Reporting Obligations

Subd. 1 – Permission to Report: A person who has knowledge of any conduct constituting grounds for discipline under sections 148.171 to 148.285 may report the alleged violation to the board.

Subd. 2 – Institutions: The chief nursing executive or chief administrative officer of any hospital, clinic, prepaid medical plan, or other health care institution or organization located in this state shall report to the board any action taken by the institution or organization or any of its administrators or committees to revoke, suspend, limit, or condition a nurse's privilege to practice in the institution, or as part of the organization, any denial of privileges, any dismissal from employment, or any other disciplinary action. The institution or organization shall also report the resignation of any nurse before the conclusion of any disciplinary proceeding, or before commencement of formal charges, but after the nurse had knowledge that formal charges were contemplated or in preparation. The reporting described by this subdivision is required only if the action pertains to grounds for disciplinary action under section 148.261.

Subd. 3 – Licensed Professionals: A person licensed by a health-related licensing board as defined in section 214.01, subdivision 2, shall report to the board personal knowledge of any conduct the person reasonably believes constitutes grounds for disciplinary action under sections 148.171 to 148.285 by any nurse including conduct indicating that the nurse may be incompetent, may have engaged in unprofessional or unethical conduct, or may be mentally or physically unable to engage safely in the practice of profes-

sional or practical nursing.

Subd. 4 – Insurers: Four times each year, by the first day of February, May, August, and November, each insurer authorized to sell insurance described in section 60A.06, subdivision 1, clause 13, and providing professional liability insurance to registered nurses or licensed practical nurses shall submit to the board a report concerning any nurse against whom a malpractice award has been made or who has been a party to a settlement. The report must contain at least the following information:

- 1 The total number of settlements or awards;
- 2 The date settlement or award was made;
- 3 The allegations contained in the claim or complaint leading to the settlement or award;
- 4 The dollar amount of each malpractice settlement or award and whether that amount was paid as a result of a settlement or of an award; *and*
- 5 The name and address of the practice of the nurse against whom an award was made or with whom a settlement was made.

An insurer shall also report to the board any information it possesses that tends to substantiate a charge that a nurse may have engaged in conduct violating sections 148.171 to 148.285.

Subd. 5 – Courts: The court administrator of district court or another court of competent jurisdiction shall report to the board any judgment or other determination of the court that adjudges or includes a finding that a nurse is mentally ill, mentally incompetent, chemically dependent, a person dangerous to the public, guilty of a felony or gross misdemeanor, guilty of a violation of federal or state narcotics laws or controlled substances act, guilty of operating a motor vehicle while under the influence of alcohol or a controlled substance, or guilty of an abuse or fraud under Medicare or Medicaid, appoints a guardian of the nurse under sections 525.54 to 525.61, or commits a nurse under chapter 253B.

Subd. 6 – Deadlines; Forms: Reports required by subdivisions 2 to 5 must be submitted no later than thirty days after the occurrence of the reportable event or transaction. The board may provide forms for the submission of reports required by this section, may require that the reports be submitted on the forms provided, and may adopt rules necessary to assure prompt and accurate reporting. The board shall review all reports, including those submitted after the deadline.

HIST: 1989 c 194 s 14; lSpl994 c 1 art 2 s 9

148.264 – Immunity

Subd. 1 – Reporting: Any person, health care facility, business, or organization is immune from civil liability or criminal prosecution

for submitting in good faith a report to the board under section 148.263 or for otherwise reporting in good faith to the board violations or alleged violations of sections 148.171 to 148.285. All such reports are investigative data as defined in chapter 13.

Subd. 2 – Investigation: Members of the board and persons employed by the board or engaged in the investigation of violations and in the preparation and management of charges of violations of sections 148.171 to 148.285 on behalf of the board or persons participating in the investigation or testifying regarding charges of violations are immune from civil liability and criminal prosecution for any actions, transactions, or publications in the execution of, or relating to, their duties under sections 148.171 to 148.285.
HIST: 1989 c 194 s 15

148.265 – Nurse Cooperation

A nurse who is the subject of an investigation by or on behalf of the board shall cooperate fully with the investigation. Cooperation includes responding fully and promptly to any question raised by or on behalf of the board relating to the subject of the investigation and providing copies of patient or other records in the nurse's possession, as reasonably requested by the board, to assist the board in its investigation and to appear at conferences and hearings scheduled by the board. The board shall pay for copies requested. If the board does not have a written consent from a patient permitting access to the patient's records, the nurse shall delete any data in the record that identify the patient before providing it to the board. The board shall maintain any records obtained pursuant to this section as investigative data under chapter 13. The nurse shall not be excused from giving testimony or producing any documents, books, records, or correspondence on the grounds of self-incrimination, but the testimony or evidence may not be used against the nurse in any criminal case.

HIST: 1989 c 194 s 16

148.266 – Disciplinary Record on Judicial Review

Upon judicial review of any board disciplinary action taken under sections 148.171 to 148.285, the reviewing court shall seal the administrative record, except for the board's final decision, and shall not make the administrative record available to the public.

HIST: 1989 c 194 s 17

148.271 – Exemptions: The provisions of sections 148.171 to 148.285 shall not prohibit:

- 1 The furnishing of nursing assistance in an emergency.
- 2 The practice of professional or practical nursing by any legally qualified registered or licensed practical nurse of another state who is employed by the United States government or any bureau, division, or agency thereof while in the discharge of official duties.

- 3 The practice of any profession or occupation licensed by the state, other than professional or practical nursing, by any person duly licensed to practice the profession or occupation, or the performance by a person of any acts properly coming within the scope of the profession, occupation, or license.
- 4 The provision of a nursing or nursing-related service by a nursing assistant who has been delegated the specific function and is supervised by a registered nurse or monitored by a licensed practical nurse.
- 5 The care of the sick with or without compensation when done in a nursing home covered by the provisions of section 144A.09, subdivision 1.
- 6 Professional nursing practice by a registered nurse or practical nursing practice by a licensed practical nurse licensed in another state or territory who is in Minnesota as a student enrolled in a formal, structured course of study, such as a course leading to a higher degree, certification in a nursing specialty, or to enhance skills in a clin while the student is practicing in the course.
- 7 Professional or practical nursing practice by a student practicing under the supervision of an instructor while the student is enrolled in a nursing program approved by the board under section 148.251.

HIST: 256 s 1; 1981 c 94 s 8; 1986 c 444: 1989 c 194 s 18 1945 c 242 s 11; 1959 c 140 s 2; 1975 c 360 s 10; 1977 c

148.281 – Violations; Penalty

Subd. 1 – Violations Described: It shall be unlawful for any person, corporation, or association, to:

- 1 Sell or fraudulently obtain or furnish any nursing diploma, license, or record, or aid or abet therein;
- 2 Practice professional or practical nursing or practice as a public health nurse under cover of any diploma, permit, license, registration certificate, or record illegally or fraudulently obtained or signed or issued unlawfully or under fraudulent representation;
- 3 Practice professional or practical nursing unless the person has been issued a temporary permit under the provisions of section 148.212 or is duly licensed and currently registered to do so under the provisions of sections 148.171 to 148.285;
- 4 Use any abbreviation or other designation tending to imply licensure as a registered nurse or licensed practical nurse unless duly licensed and currently registered so to practice professional or practical nursing under the provisions of sections 148.171 to 148.285 except as authorized by the board by rule;
- 5 Use any abbreviation or other designation tending to imply

registration as a public health nurse unless duly registered by the board;

- 6 Practice professional or practical nursing in a manner prohibited by the board in any limitation of a license or registration issued under the provisions of sections 148.171 to 148.285;
- 7 Practice professional or practical nursing during the time a license or current registration issued under the provisions of sections 148.171 to 148.285 shall be suspended or revoked;
- 8 Conduct a nursing program for the education of persons to become registered nurses or licensed practical nurses unless the program has been approved by the board; and
- 9 Knowingly employ persons in the practice of professional or practical nursing who have not been issued a current permit, license, or registration certificate to practice as a nurse in this state.

Subd. 1a: Repealed, 1989 c 194 s 22

Subd. 2 – Penalty: Any person, corporation, or association violating any provisions of subdivision 1 shall be guilty of a gross misdemeanor, and shall be punished according to law.

HIST: 1945 c 242 s 12,13; 1959 c 140 s 4; 1975 c 360 s 11; 1977 c 256 s 2; 1986 c 444; 1989 c 194 s 19

148.283 – Unauthorized Practice of Professional and Practical Nursing

The practice of professional or practical nursing by any person who has not been licensed to practice professional or practical nursing under the provisions of sections 148.171 to 148.285, or whose license has been suspended or revoked, or whose registration has expired, is hereby declared to be inimical to the public health and welfare and to constitute a public nuisance. Upon complaint being made thereof by the board, or any prosecuting officer, and upon a proper showing of the facts, the district court of the county where such practice occurred may enjoin such acts and practice. Such injunction proceeding shall be in addition to, and not in lieu of, all other penalties and remedies provided by law.

HIST: 1959 c 140 s 6; 1989 c 194 s 20

148.285 – Transfer of Assets

All moneys, property, and property rights belonging to and under the control of the board of examiners, are hereby transferred and appropriated to the control and use of the board hereunder and the purpose provided herein.

HIST: 1945 c 242 s 14

Appendix H

Comparison of LSN & SHP Roles

LSN	SHP
Health Room Organization	
• Plans weekly schedule • Plans room arrangement • Plans activities for health program • Determines stock needed	• Implements plans as specified by LSN • Keeps room organized • Maintains inventory and orders supplies
Health Assessment	
• Assesses individual children	• Assists with monitoring, reporting, documenting
Individual Health Planning	
• Develops, implements, & assists in evaluating IEP	• Carries out plan to meet the child's health needs
Individual Educational Planning	
• Assesses individual children	• Carries out plan as appropriate
Health Counseling	
• Counsels based on the individual & group needs based on assessment	• Reinforces health concepts during individual student contact
Teaching	
• Provides info on resources • Teaches classes on request	• Orders resources on request • Types/duplicated materials
Behavior Management	
• Plans behavior mgt. strategies for students based on IEP or IHP	• Implements behavior mgt. strategies with same emphasis techniques as other staff
Working with Parents	
• Meets with parents • Initiates conferences on child's health	• Facilitates nurse-parent communication • Sends out memos; schedules meetings and conferences

Appendix I

Statement on the Nursing Activities of Unlicensed Persons

Purpose

The purpose of the National Council of State Boards of Nursing (NCSBN) in formulating this statement is to provide information to jurisdictions regarding the regulation of nursing acts performed by unlicensed persons.

Introduction

Unlicensed persons performing nursing acts has been a concern since the early 1900s. In the early 1900s the establishment of standards of nursing led to the formation of boards of nursing. Early licensing laws delineated the educational preparation required to become a nurse; however, they did not define nursing practice. Anyone who had successfully completed the requisite training program and examination was identified as a registered nurse.

Because nursing practice lacked definition, anyone could perform nursing functions as long as they did not identify themselves as nurses. However, the care that was provided then was custodial in nature because nursing care consisted of assisting with the activities of daily living. Because of the simplicity of nursing tasks in that time, it is not surprising that unlicensed persons learned on the job how to give custodial care.

Today, unlicensed persons are trained on the job or in short-term training programs and are employed to perform nursing acts or functions that range from custodial to complex. These ever-expanding job roles for unlicensed persons are of growing concern to the nursing and consumer communities. Some of the possible reasons for the increase of nursing acts being performed by unlicensed persons and the role of boards of nursing in this issue will be addressed.

Through the years, health care, including nursing, has become far more sophisticated. Nursing is no longer a compilation of tasks and caring related to daily living. The process of caring and doing in nursing are now integrated with technology. The integration of knowledge, judgment and skill is needed to practice nursing. As a result, the field of nursing has come to recognize the need for academic preparation for its practitioners.

The image of nursing commonly held by the public and many employers is that the intellectual component is not essential to the

practice of nursing. This misperception of nursing has not changed even as the complexity of client's problems and need for care has increased; thus, the job market within nursing of unlicensed persons has increased.

The 1960s and 1970s focused the nation's attention on improving the availability of health care for all. With the inauguration of Medicare and Medicaid programs and widespread availability of comprehensive health insurance, approximately ninety percent of all health care services were being reimbursed by third party payers by 1981. The public policy that promoted third party reimbursement added little incentive to health care providers to economize. As a result, within this time frame, the cost of health care tripled in the United States.

Other costly shifts took place in the health care system beginning in the 1970s. Public policy changes expanded or relocated services so that these evolved a demand for health care, especially nursing services, in a more settings than had ever been experienced. De-institutionalization caused many services to be shifted into the community. Also occurring in this period was an emphasis on health care as a right rather than a privilege. Changes in public policy promoting accessibility of care for all increased the public's expectation for care in many arenas and not just in the traditional physician's office, hospital, or nursing home.

There are many examples of how public policy made health care more widely accessible, often in previously underserved areas. Handicapped children who had previously been institutionalized or uneducated were mainstreamed into the public school classrooms, requiring schools to provide more complex health services. The chronically mentally handicapped were de-institutionalized and often needed community-based health services. Communities made strides in improving the quality and availability of emergency services which required increased manpower. In response to societal changes, prisons began to provide health care services to inmates, requiring staff who could provide these health services.

Related changes occurred even in the traditional facilities. Chronic care once provided in hospitals was shifted to long term care facilities or to home settings because more of the chronically ill were simply living for much longer periods of time and were requiring care during their expanded lifespans. The elderly population also rose with better standards of living and better health care. More nursing homes were built to care for the elderly and for those with chronic debilitating illnesses, while the need for care in people's private homes continued to grow as well. These examples reflect how more people came to expect broader services as a result of public policies.

Formerly, many of these services were unavailable or were available from nurses and those they supervised in institutions. Now community settings were responsible for providing health care which was mainly nursing care. This care was often needed on an

intermittent or part time basis and at low cost. Nurses simply were not available in sufficient numbers or were not hired because of cost. These forces resulted in unlicensed persons, who frequently lacked any institution or supervision by nurses, carrying out ever increasing complex care.

The use of unlicensed persons was also encouraged by many health care businesses. The possibility of making large profits through the expanded third party reimbursement mechanisms gave birth to many health care businesses. These businesses often chose to use unlicensed persons in order to keep profits high.

In the 1980s, the public policies that stimulated runaway growth in the health care industry came under criticism. Americans expected accessible, quality health care for all segments of the population, but were unable to afford the rising health care costs. In order to control escalating costs, the health care industry was coerced into implementing cost containment measures by the government, the industrial community, and the insurance industry.

With cost containment came greater increasing demand for home care delivery and even greater efforts from health care businesses to use unlicensed persons. Because nursing services are required on such an ongoing intensive basis, they are a substantial budgetary item. Thus the price of unlicensed staff members continues to be attractive.

Another justification used for employing unlicensed persons has been the current nursing shortage. This argument is weak because the impetus for unlicensed persons to be hired to perform nursing services has existed in times of abundant supply of nurses as well as in shortages. At this time there are nurses, especially LPNs, who are available in places where they are being bypassed in favor of unlicensed and unregulated persons.

Today one of the driving forces to hire unlicensed personnel is largely financial in nature. The one time concerns of the previous decades regarding accessibility and quality which brought runaway costs have now been controlled and the patterns of care is determined by the money available. Unlicensed persons remain an attractive substitute to employers who often hold the common misconceptions about nursing and who have serious financial concerns.

This inappropriate use of unlicensed persons to perform nursing act at a lesser cost than nursing care provided by nurses is placing the public health, safety, and welfare at risk. Unsafe care results in higher mortality rates, greater morbidity, unnecessary suffering, and increased utilization of both inpatient and outpatient facilities. The nursing profession has historically demonstrated its responsibility to the public to deliver high quality nursing care by supporting the licensing of nurses, the formulation of standards of nursing practice, and the passage of legislation for mandatory licensure. The threat to the public now caused by the increasing pressure to use unlicensed persons is reason again for boards to take action.

Rationale for Board Involvement

Since the role of the Board of Nursing in each jurisdiction is to protect the health, safety, and welfare of the public by regulating nursing practice, Boards of Nursing have a legitimate concern and have the legal responsibility to monitor any and all nursing activities. This responsibility and its attendant powers are delegated to the Board by the state legislature to fulfill the state's constitutional obligation to protect its citizens. Statutes are enacted by the legislature to grant power to the Board and to provide general mandates pertaining to the regulation of nursing. The statutes also empower and even mandate the Board to adopt applicable administrative regulations.

When the registered nurse delegates selected nursing functions or tasks, the responsibility and accountability to the public for the overall nursing care remains with the registered nurse. Administrative rules often provide what functions or tasks may or may not be delegated and under what conditions delegation may be made. The burden of determining the competency of the person who will perform the tasks and of evaluating the situations rest with the licensed nurse.

Because unlicensed persons perform tasks and functions in one or more of the several categories which constitute the practice of nursing without a license, the Board of Nursing must be involved in their activities. These categories of type of practice by unlicensed persons are:

- Little or no institution or supervision by licensed persons.
- Minimal instruction with return demonstration of particular task with no follow up supervision by licensed persons.
- Limited to moderate instruction with return demonstration of particular task under supervision by licensed persons.
- Moderate to ample instruction with return demonstration of particular task under supervision of licensed persons functioning adequately in assigned areas.

In each instance when the unlicensed persons perform nursing functions without the benefit of instruction or supervision by nurses, this constitutes the practice of nursing without a license and, therefore, should be a concern to the Board of Nursing.

Boards are receiving many requests to allow unlicensed persons to give medications in a variety of settings serving dependent persons. The argument frequently given is that it is a simple technical skill. While this may be true in a few other unique situations, these dependent persons have a high incidence of complex nursing care needs and a high percentage of chronic illness. Hence the nurses' knowledge, judgment and skill are needed to prevent aspiration, to prevent over and under medication, to administer sliding scale insulin, to administer medications by other than the oral

route, and to assess and determine when to administer the multiplicity of p.r.n. medications.

Arguments presented by those who would use unlicensed persons to do complex nursing tasks usually include, for example, "you teach the family to give insulin, to give morphine, to irrigate colostomies". The primary differences with family members are that family members know the patient or client well; family members are only performing the activity for one person; and a nurse has assessed the client, made a nursing diagnosis and planned the care. The nurse teaches the family members what to do for that one client. The nurse evaluates the competency of the family members and instructs them accordingly. When something unexpected occurs, the family members will call the nurse who taught them and this nurse can re-evaluate the entire situation. The change is gauged easily by a family member because of the familiarity with the person gained over a long period of time. This familiarity is not afforded the unlicensed person giving care.

In contrast, the unlicensed person may be doing a task for many clients who are usually not well known to the worker but with a multiplicity of needs.

The unlicensed person has been taught to do a task in a general way but without the knowledge to evaluate each client's needs or problems. The unlicensed persons' lack of knowledge, skill and judgment becomes apparent in their inability to adapt care to individuals' needs based on anything other than rudimentary decision making. Adaptation of care to individual needs requires nursing decisions. Without adequate nursing involvement in the education and supervision of unlicensed persons, patients can be subject to unskilled persons doing nursing tasks without any appreciation of their psycho-social or physical needs. Further, unlicensed persons are reluctant to call for help for fear of being judged incompetent.

Hence, there is a clear difference between care delivered by a family member and that delivered by a paid unlicensed person.

Documenting the Problem

A questionnaire on the activities of unlicensed personnel was circulated to member boards in 1986 with a 71% response rate. The data identified activities by unlicensed and unauthorized personnel to include such things as administration of medications (oral, intramuscular, subcutaneous, intravenous); fresh colostomy irrigations; peritoneal dialysis; and a variety of other nursing activities requiring a nurse's knowledge and judgment. Boards of Nursing responding to the survey reported considerable concern, especially over the wide reporting of administration of medication by a variety of unauthorized personnel in a multiplicity of settings.

The following table summarizes examples of inappropriate utilization of unlicensed personnel:

Population of Recipients	Setting	Source of Problem
1 Individuals of all age groups with non-acute health problems	Physicians' offices	Physician delegation clauses in medical practice acts
2 Dependent persons (persons unable to exercise their rights without assistance)		
a Mentally handicapped	Group homes, community living arrangements, intermediate care facilities, or institutions	State dept. of health or federal guidelines which are misinterpreted or misapplied
b Elderly	Boarding homes, nursing homes, community living arrangements	Dept. of aging or federal guidelines which are misinterpreted or misapplied
c Children (all ages)	K-12 schools, Head Start ctrs., nursery schools	Dept. of education guidelines which are misinterpreted or misapplied
d Chronically ill	Homes, skilled care nursing homes, hospices	Dept. of health and welfare guidelines which are misinterpreted or misapplied
3 Prison populations	Prisons and detention ctrs.	Dept. of criminal justice or corrections dept. regulations which are misinterpreted or misapplied
4 Populations served by non-nurse anesthetists, lay midwives, dialysis technicians, and EMTs	Hospitals, doctors' offices, various settings	Physician delegation clauses in medical practice acts and health dept. guidelines which are misinterpreted or misapplied

Definitions

The following operational definitions are presented as a means to establish common understanding of the terms used in this article:

- **Accountability:** State of being responsible, answerable, or legally liable for action.
- **Delegation:** Nurses entrusting the performance of selected nursing tasks to competent unlicensed persons in selected situations. The nurse retains the accountability for the total nursing care of the individual.
- **Judgment:** A process of forming an opinion or evaluation of a

situation arrived at by reasoning discerning and comparing from premises or general principles.

- **Knowledge:** Understanding, familiarity or awareness acquired through science, art, technique, and experience where known fact, ideas, and skill has been applied.
- **Nurse:** Generic term referring to a person licensed to practice nursing.
- **Nursing practice:** The NCSBN Model Nursing Practice Act defines the practice of nursing as assisting individuals or groups to maintain or attain optimal health status, establishing a diagnosis, planning and implementing a strategy of care to accomplish defined goals, and evaluating responses to care and treatment.
- **Skill:** The ability to use one's knowledge, judgment, and competency effectively and readily in performing a learned psychomotor task.
- **Supervision:** Provision of guidance by a qualified nurse for the accomplishment of a nursing task or activity with initial direction of the task or activity periodic inspection of the actual act of accomplishing the task or activity. Total nursing care of an individual remains the responsibility and accountability of the nurse.
- **Teaching (Instruction):** Includes giving information and ascertaining that the information has been learned through a return demonstration.
- **Unlicensed Personnel:** Unlicensed persons are individuals who are unauthorized to perform nursing acts or tasks that are regulated by the Board of Nursing except pursuant to legal delegation by the nurse. Three categories of unlicensed personnel are identified as follows:
 - Those to whom nurses delegate and supervise;
 - Those whom nurses teach but do not supervise;
 - Those who are not directly or indirectly supervised or taught by nurses.

Conclusions

- Performance of non-nurse delegated and non-nurse supervised nursing activities by unlicensed persons constitutes practicing nursing without a license and is not in the interest of the health, safety, and welfare of the public.
- Language in nursing practice acts that allow for supervision of nursing activities by non-nursing persons is inappropriate.
- The interpretation of physician delegation clauses in medical practice acts that allows for physicians' delegation of nursing acts is inappropriate
- Pieces of care should not be provided in isolation by unli-

censed persons functioning independently of the nurse if the health, safety, and welfare of the public is to be assured.

- Boards of Nursing need to monitor guidelines and regulations of federal and state regulatory agencies with the understanding that the state's Nursing Practice act has the higher legal authority.
- Boards of Nursing need to work to assure evidence of adequate nurse involvement where nursing services are being provided.
- Boards should promulgate clear rules on the utilization of unlicensed persons in all settings where nursing care is delivered.
- Boards need to clearly define delegation in regulation.
- A limited supply of nurses is not an excuse for the inappropriate utilization of unlicensed persons.
- Boards must set standards based on the health, safety, and welfare of the public regardless of cost containment arguments for lowered standards.
- Regulations regarding the delegation of nursing functions must be linked to the disciplinary process.
- Boards need to pursue criminal prosecution when there is clear evidence that unlicensed persons are performing nursing activities.

References

Pagin, C. "Nursing's Pivotal Role in American Health Care." In L. Aiksas (Bd.) *Nursing in the 1980s, Crisis, Opportunities, Challenges*. Philadelphia: J.B. Lippincott Company. 1982.

National Council of State Boards of Nursing, Inc. *Book of Reports. Nursing Practice and Standards Committee Report to the Delegate Assembly on Activities of Unlicensed Personnel*. 1986

National Council of State Boards of Nursing, Inc.

The Model Nursing Practice Act. 1982

Appendix J
Sample IHP Form

Individualized Health Plan

Identifying Information

Student ID _____	IHP initiation date _____
Name _____	Date of birth _____
Address _____	Grade _____ Teacher _____
_____	School _____
Parent/Guardian _____	Telephone [H] _____
	[W] _____
Health care provider(s) _____	
_____	Telephone(s) _____
Special health needs(s) [Presenting problem(s)] _____	

May result in an emergency:	No ☐ Yes ☐	>	Health planning conference	Date _____
May interfere with learning:	No ☐ Yes ☐	>	Refer to child study team	Date _____
Other health impairment:	No ☐ Yes ☐	>	a) Health planning conference	Date _____
			b) Refer to child study team	Date _____

Assessment

Health history/present status/health practices:

Interviewer _____ Interviewee _____ Date _____

Sensory assessment:

Assessor _____ Date _____

Physical assessment:

Assessor _____ Date _____

Developmental assessment:

Assessor _____ Date _____

Findings:

Nursing diagnosis:

[Individualized Health Plan – continued]

Health Planning Conference _____ Date _____
[for health needs that may result in an emergency and/or require management or monitoring]

Participants

Roles

_____	_____
_____	_____
_____	_____

Goals

Objectives

Timeline

_____	_____	_____
_____	_____	_____
_____	_____	_____
_____	_____	_____
_____	_____	_____
_____	_____	_____
_____	_____	_____
_____	_____	_____
_____	_____	_____
_____	_____	_____

Implemented by

_____	_____
_____	_____

Monitored by

_____	_____
_____	_____

Evaluation/Follow-up Plan _____ Date _____

Parental approval

Case manager

_____	_____
-------	-------

Appendix K
Sample IEP Form

	INDIVIDUAL EDUCATION PROGRAM (IEP) PLAN		DATE
			IEP Written:
			Periodic Review Due:
			Last Comprehensive Assessment:

A. LEARNER INFORMATION				
Leamer's Name <i>Jessie Johansen</i>	Gender <i>F</i>	Grade <i>12</i>	Birthdate <i>12-31-75</i>	ID Number <i>122-34-5678</i>
Street Address <i>406 Amy Lane</i>		Primary Language / Communication Mode <i>English, Verbal</i>		
City, State, Zip <i>Swanville, MN 56666</i>				
School of Enrollment <i>Swanville High School</i>		School Phone <i>(612) 123-4567</i>	District Number <i>123</i>	
Leamer's Permanent Resident Address <i>same</i>			Resident District Number <i>123</i>	

B. PARENT/GUARDIAN INFORMATION			
Name(s) of Parent(s) <i>Mark and Joan Johansen</i>		Phone <i>123-4567</i>	Phone
Parent(s) Address (if different) <i>same</i>		Primary Language <i>English</i>	District Number <i>123</i>
Guardian(s) / Surrogate Parent(s) Name(s) <i>same</i>		☒ Guardian(s) ☐ Surrogate Parent(s)	
Guardian(s) / Surrogate Parent(s) Address (if different) —		Home Telephone	Other Telephone District Number

C. IEP INFORMATION			
Primary Disability <i>Learning Disability</i>	Federal Childcount Setting <i>Regular Education</i>	IEP Type ☐ Initial ☒ Annual ☐ Interim	
IEP Manager Name <i>Sue Hanson</i>	Position <i>Special Education Teacher</i>	Telephone Number <i>345-6789</i>	

D. IEP PLANNING MEETING		
Title	Names of All Team Members	Signature (if present)
Parent	<i>Mark Johansen</i>	
Parent	<i>Joan Johansen</i>	
Learner	<i>Jessie Johansen</i>	
Administrator or Designee	<i>Sarah Hoffman</i>	
Special Education Teacher	<i>Sue Hanson</i>	
Regular Education Teacher (K-12 only)	<i>Tim Johnson</i>	
<i>sister</i>	<i>Cindy Johansen</i>	
<i>SSB counselor</i>	<i>Harold Batens</i>	
<i>School guidance counselor</i>	<i>Mildred Fortney</i>	
<i>Support Services, .MTC</i>	<i>Sharon McElroy</i>	

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COPIES:

☐ Learner File☐ Parent☐ IEP Manager

Learner's Name: _____

Jessie Johansen

E. PRESENT LEVELS OF PERFORMANCE & LEARNER-BASED NEEDS	
Carefully consider and document data from all sources in the following areas: (Include information and observations provided by parent[s] and learner.) • Intellectual / Cognitive Functioning • Academic Performance • Communicative Status • Motor Ability • Sensory Status • Health / Physical Status • Emotional and Social Development • Behavior and Functional Skills * † • Secondary Transition (must be summarized for all learners who have reached 9th grade or age 14) A. Jobs and Job Training B. Recreation and Leisure C. Home Living D. Community Participation E. Post-Secondary Training and Learning Opportunities * Identify post-school outcomes for each transition area. † If the team determines that there are no transition needs in one or more areas, write a statement to that effect and the basis for this determination.	
PRESENT LEVELS OF PERFORMANCE	LEARNER-BASED NEEDS
Post-secondary Education <i>Future adult goal: I want to work in the law enforcement field, maybe as a dispatcher. I plan to go to a post-secondary school that has training in law enforcement.</i> <i>Present level of performance: I have been a police explorer for two years. I have visited several technical colleges and community colleges and have checked into housing and public transportation at each site. I keep track of all this information in my transition folder. I understand my personal strengths and weaknesses and have learned how to advocate for the accommodations I need to be successful.</i>	<i>I need to apply at the postsecondary schools I like the best, figure out how to pay for it, and work at getting the accommodations I think I will need to successfully complete the program.</i>

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Learner's Name:

Jessie Johansen

F. ANNUAL INSTRUCTIONAL GOALS & SHORT-TERM OBJECTIVES		
GOAL In writing the goal statement, indicate the direction of change, the behavior to be changed, and the expected ending level of performance.		GOAL # ____ OF ____ GOALS
<i>I will increase preparation activities for fall, 1994, entry into a post-secondary school that offers a program in my interest area from having visited several schools to completing an application and being accepted, finding financial aid, and setting up accommodations by graduation this spring.</i>		
SHORT-TERM OBJECTIVES There must be more than one objective for each goal. For each objective include attainment criteria and evaluation procedures.	Review Date	Degree of Progress
1. <i>Given registration materials for post-secondary school of interest, I will complete the necessary forms with 100% accuracy by the end of the first semester as determined by my school counselor.</i> 2. <i>Based on my learning strengths and weaknesses, I will correctly list all the resources available at the schools I am interested in before enrolling, as determined by my special education teacher.</i> 3. <i>I will travel by city bus to my SSB counselor's office and meet with my counselor at least four times over the course of the school year for assistance in planning and funding my post-secondary education as monitored by my SSB counselor.</i>		

G. PERIODIC REVIEW SUMMARY OF GOAL & OBJECTIVES
The following is the status of the learner's goal and objectives:
☐ Goal achieved.
☐ Meets learner's current needs and will be continued without changes.
☐ The non-significant changes listed below will be made without an IEP meeting unless you contact us.
☐ Does not meet learner's current needs and the significant changes listed below require a revised IEP. We will be in contact soon to schedule a meeting.
NOTE TO PARENT(S): You are entitled to request a meeting to discuss the results of this review.

Learner's Name: Jessie Johansen**H. SPECIAL EDUCATION & RELATED SERVICES****SPECIAL EDUCATION SERVICES**

SER- VICE PER- SONNEL CODE <i>(see reverse for codes)</i>	NAME OF SERVICE PROVIDER & PHONE NUMBER	SER- VICE CATE- GORY CODE <i>(see reverse for codes)</i>	BUILDING NAME & ROOM NUMBER	FRE- QUENCY	MINUTES PER WEEK		TYPE OF SETTING						DATE SERVICE BEGINS	DURA- TION OF SER- VICES		
					INDIRECT	DIRECT	check one			check one						
							CLASS	GROUP	INDIVIDUAL	GENERAL	SPECIAL	INTEGRATED			OTHER	
01	Sue Hanson 345-6789	490	Swanville High, Rm 207	daily	75	150		x				x			9-93	6-94

RELATED SERVICES AND JUSTIFICATION

35	Mildred Fortney 456-7890	35	Swanville High, Rm 101	monthly		10			x	x				9-93	6-94
----	-----------------------------	----	---------------------------	---------	--	----	--	--	---	---	--	--	--	------	------

Justification: *Information about postsecondary schools, application process, and accommodations*

--	--	--	--	--	--	--	--	--	--	--	--	--	--	--	--

Justification:

TRANSITION SERVICES (for age 14 and above)

AGENCY NAME	NAME OF SERVICE PROVIDER & PHONE NUMBER	BUILDING NAME	FREQUENCY	AMOUNT OF SERVICE TIME	DATE SERVICE BEGINS	DURATION OF SERVICES
State Services for the Blind	Harold Batens 426-1234	Park Plaza	at least quarterly	minimum 8 hours	10-93	ongoing

Interagency / Organization Linkages (Identify activities, funding responsibilities, etc.):
assistance in planning and funding postsecondary education

Support Services Morton Tech. College	Sharon McElroy 426-9876	Morton Tech College	as needed	about 4 hours	10-93	throughout college career
---	----------------------------	------------------------	-----------	---------------	-------	------------------------------

Interagency / Organization Linkages (Identify activities, funding responsibilities, etc.):
provide information on technical college options and accommodations

Learner's Name: Jessie Johansen**L ADAPTATION OF GENERAL & SPECIAL EDUCATION**

Describe changes in general and special education that will be made to permit successful accommodation and education of the learner (e.g., grading, credits, staff, transportation, facilities, materials, equipment, technology, adaptive devices, curriculum, methods, coordination of support services, vocational services and equipment, and other services):

Are Regulated Behavioral Interventions required for this learner?

☐ Yes ☐ No

(If yes, attach behavior plan as described in M.R. 3525.2925.)

Are general education secondary graduation standards being modified?

☐ Yes ☐ No

(If yes, attach team determination documentation as described in M.R. 3525.3150.)

Are extended school year services required for this learner?

☐ Yes ☐ No

(If yes, attach extended school year justification as described in M.R. 3525.2900 Subp. 1.H.)

J LEAST RESTRICTIVE ENVIRONMENT (LRE)

Explain why the proposed placement is the most appropriate and the least restrictive. (Describe any other options considered.)

K DESCRIPTION OF ACTIVITIES WITH LEARNERS WITHOUT DISABILITIES

For a learner who is served more than half-time in a special education setting, include any activities in which the learner will be participating with learners who do not have disabilities (e.g., lunch, assembly periods, club activities, field trips, community instruction or experiences, and other special events):

Activity	Frequency	Amount of Time

LENGTH OF DAY

☐

Check here if the learner's school day is shorter than that of peers without disabilities.
(If checked, Commissioner of Education approval is required.)

NOTE:

Attach "Notice of Special Education Services."

Service Personnel Codes

- 01 Teacher
- 02 Supervisor / Coordinator
- 03 Lead Teacher
- 04 Physical Therapist
- 05 Occupational Therapist
- 06 School Nurse (*Report only time in levels V and VI.*)
- 07 Program / Instructor Assistant Levels I, II, III
- 08 Program / Instructor Assistant Levels IV, V, VI
- 09 Director of Special Education
- 10 Assistant Director
- 11 School Social Worker
- 12 School Social Worker Aide for Indian, Hispanic, or Southeast Asian Students
- 13 School Psychologist
- 14 Audiologist
- 15 Adaptive Physical Education Specialist
- 16 Consultant
- 17 Other
- 18 Child Find Facilitator
- 19 Public Information Facilitator
- 20 Child Study Due Process Facilitator
- 21 Alternative Program Facilitator
- 22 Secretary
- 23 Substitute Teacher
- 24 Certified Occupational Therapy Assistant (COTA)
- 25 Other Certified Therapist
- 26 SEIMC Management Personnel
- 27 Vision Media Assistant (brailist / L.P. typist)
- 28 Interpreter for the Deaf
- 29 Orientation and Mobility (O & M)
- 30 Due Process Hearing Officer
- 31 Clinical Psychologist
- 32 Behavior Analyst (prior approval)
- 33 Regional Special Programs Supervisor
- 34 Assistive Technology Specialist
- 35 School Counselor

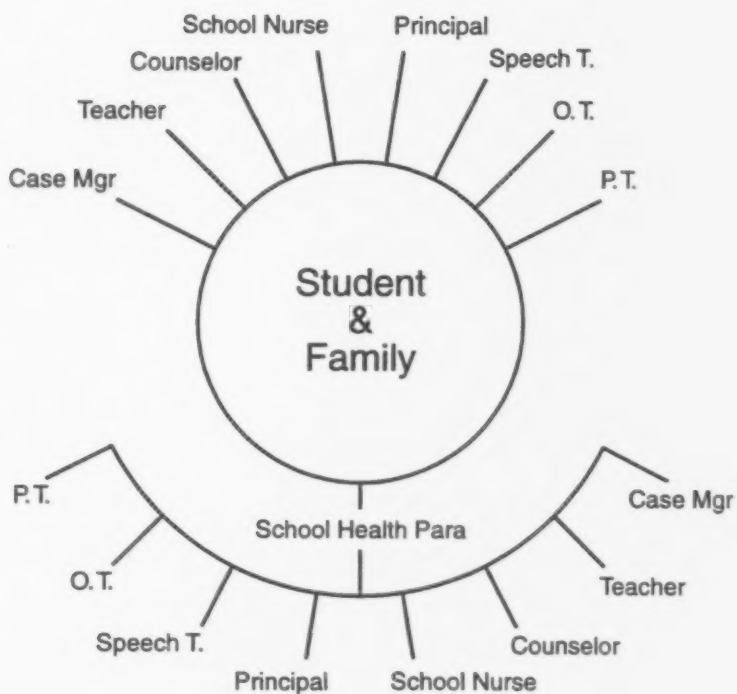
Service Category Codes

- 425 Early Childhood Handicapped
- 440 Mildly Mentally Impaired
- 450 Moderately Severe Mentally Impaired
- 460 Physically Handicapped
- 465 Hearing Impaired
- 470 Speech / Language Impaired
- 475 Visually Handicapped
- 490 Specific Learning Disability
- 491 Other Health Impaired
- 492 Autistic
- 493 Emotional / Behavioral Disorder
- 494 Traumatic Brain Injury

Appendix L

"Chain of Command"

Diagram



Appendix M

Body Mechanics

Explain the
Procedure



Squat



Get Help



Lift with
Thigh
Muscles



Have a
Wide
Base of
Support



Be Smooth
and
Synchronized



Move in
Close



Turn with
Your Feet



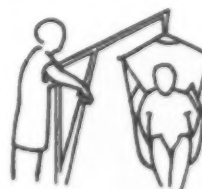
Use an
"Internal
Girdle"



Push or Pull



Use
Lifting
Aids



Appendix N

Diapering Procedure

Preparation

- 1 Wash hands with soap and running water.
- 2 Assemble supplies within reach:
 - Clean disposable diaper
 - Disposable wipes or paper towels
 - Roll paper or nonabsorbent paper sheets
 - Disposable gloves (when used)
 - Optional: ointment, cotton swabs, clean clothing
- 3 Cover diapering table and waste bin lid with nonabsorbent paper. The table needs to be the length of the child; leave about a twelve inch overhang at the feet or have clean paper sheets within reach.
- 4 Put gloves on.

Contamination

- 1 Put the child on the table. Keep one hand on the child the entire time he or she is on the table. Keep others away from the diapering area. Remove the child's clothing; put soiled clothing aside.
- 2 Remove the soiled diaper. Loosen diaper tabs; roll diaper inward. Using the foot pedal to open, place the diaper directly into the waste bin or place it on the paper-covered lid. (It must be out of the child's kick space or reach.)
- 3 Cleanse the diaper area of the child. Clense from front to back and include skin creases. Use the child's own disposable wipes or the three paper towel method (soapy-rinse-dry). Place the wipes in the waste bin or on its lid. Dry child's skin well.
- 4 Remove gloves and place them in/on waste bin.

Cleaning Phase

- 1 Put clean paper under the child; fold the overhang at the feet or use a clean sheet.
- 2 Use ointment as ordered; apply with clean swabs or gloves.
- 3 Diaper and dress the child.
- 4 At the sink, use soap and running water to wash both your hands and the child's.
- 5 Return child to the play area.

Clean-up

- 1 Dispose of soiled items: Place diaper in a small bag (optional). Put diaper, wipes, paper towels, changing paper, cotton swabs,

and gloves into the plastic-lined, foot-operated waste bin. Put any soiled clothing in a plastic bag for parent to take home.

- 2 Clean and disinfect the diapering table, waste bin lid, and faucet handles.
- 3 Wash hands with soap and water for twenty seconds using the posted procedure.

Communicate

- 1 Record the diaper change.
- 2 Report any concerns to parents (unusual color, odor, frequency, or consistency of stool; rash).

Appendix O

Hand Washing Flyers

HANDWASHING

PROCEDURE

The single most effective thing you can do to prevent the spread of disease is to correctly wash your hands and the children's hands thoroughly and often.

BOTH STAFF & CHILDREN WASH:

HOW

- 1 Remove jewelry; push up sleeves. **Wet** hands with warm, running water ($110^{\circ} \pm 10^{\circ}$ F).
- 2 **Apply** liquid soap.
- 3 **Wash** hands for 20 seconds; include palms, backs, between fingers, thumbs, fingernails, and wrists. Use a nail brush after contact with stool or if a food handler.
- 4 **Rinse** well with fingertips pointed down.
- 5 **Dry** hands with a hot air dryer or a paper towel.
- 6 **Turn off faucet** with a paper towel. This avoids contamination. Throw paper towel into a plastic-lined waste container.

WHEN

- When you **arrive**.
- Before or after you eat; before you prepare or serve **food** or set the table.
- Before you prepare or give **medication**.
- After using the toilet; before and after **diaper** changes.
- After you handle items or children soiled with **body fluids or wastes** (blood, vomit, stool, urine, drool, eye matter).
- After you cough, sneeze, or blow your **nose**.
- After playing with or caring for **pets**.
- After playing **outside**.
- Before and after using water tables or **moist items** like clay.
- Whenever hands **look, feel, or smell** unclear.

Adapted from materials prepared by Hennepin County Community Health Department with the support of epidemiologists and child health care consultants from the Twin Cities area state and local health departments.

HANDWASHING

STEPS



1 • WET



2 • SOAP



3 • WASH



4 • RINSE



5 • DRY



6 • TURN OFF WATER

Appendix P

Questions to Ask Regarding Doctors' Services

You may want to share this handout as a reference for parents who are living with an individual who is medically fragile or has a physical disability.

Questions to Ask Before a Doctor Sees Your Child

When Interviewing Doctors by Telephone

- 1 Do you see children with disabilities in your practice?
- 2 Do you have experience with children who have (your child's disability)?
- 3 Would you be comfortable working in a medical team situation with other doctors who will be seeing my child?
- 4 Can you schedule extra long appointments?
- 5 Who sees your patients when you are not available?
- 6 Which hospital do you use for patients who require hospitalization or hospital tests?
- 7 What are the facilities of this hospital for children and families like mine?
- 8 If my child were hospitalized, would I be allowed to stay with him or her?
- 9 After you've examined my child, can you arrange for one of your staff to watch him or her for a few minutes so we can talk alone?
- 10 Would there be any additional charges for any of these arrangements?

When Scheduling an Appointment

- 1 I will be needing a longer appointment than most families. Can we schedule a time when we can have a double appointment?
- 2 My child has difficulty waiting patiently: is the first appointment of the morning available or one right after lunch break?
- 3 If you don't make appointments, what times of day or which days of the week are least busy?

Questions to Ask When a Doctor Has Seen Your Child

Questions about an Illness

- 1 Can you make a diagnosis at this time?
- 2 Would you recommend a second opinion or a specialist for this illness?
- 3 Should anything be done immediately? What should we be doing over the next few days? Are there any long-term needs/concerns?
- 4 When will the child begin to feel better? How long does this illness usually last?
- 5 Are there any symptoms I should be aware of to monitor this illness? What are the indications that he or she is getting better? What are the indications of any complication or worsening?
- 6 If I do notice any signs of complications, how can I contact you after office hours? In an emergency, whom should I call?
- 7 When can he or she go back to school? Are there any special precautions of which the school should be aware?

Questions about General Check-ups and Development

- 1 Is he or she within the range of normal height and weight for his or her age? Is he or she growing at a normal rate?
- 2 Is he or she developing normally in the areas of physical abilities, speech, vision and cognitive development?
- 3 What are the age ranges typically during which children develop these abilities? Am I right to be concerned at this time? When should I become concerned?
- 4 Do you think some developmental screenings should be done at this time? Do you administer any of these tests yourself as part of the regular check-up? (If the answer is no, you may want to have the doctor write a report indicating a concern over development in a particular area which you can send to the school staff working with your child to request that they test your child or arrange for appropriate testing. If your child is not school age, you may request these results be sent to the school system to request early intervention screening.
- 5 What are the next developmental stages we should be watching for? What can we do to help our child?
- 6 Should we be consulting with the early intervention program and/or therapists for our child? Will you collaborate with the school by sending copies of your evaluations or writing a report specifying my child's delays which I can use in talking to the local school system?
- 7 Can I give the school or early intervention team your phone number so they can call if they have any questions?

- 8 Do you think we should be consulting with any other specialists at this time? If yes, what are your recommendations? Can you refer us?

Questions about Medications

- 1 When should I give this medication?
- 2 When the prescription says "three times a day" does that mean every eight hours including during the night, or three times during the daytime?
- 3 When my child goes back to school, will he need to take this medicine during school hours or can it wait until he gets home?
- 4 Should the child take this medication before, during or after meals?
- 5 Are there any foods which should not be mixed with this medication?
- 6 How long should he take this? Should he finish the bottle or stop when the symptoms go away?
- 7 If your child has other medications he is currently taking talk about those work and how they do not work together.
- 8 Can he take this medicine at the same time? Are there any possible side effects or allergic reactions I should be aware of? How will I recognize them? What should I do if I think he or she is having a reaction?
- 9 Does this medicine need to be stored at a special temperature, that is, does it go bad if the medicine gets too hot or too cold?

Questions about Tests

- 1 What do you expect to learn from these tests?
- 2 Have these tests been given to my child before? Can we coordinate any of the earlier results with these?
- 3 Does the school or public health clinic also do these tests? Is there any reason not to have them done there to save on expenses?
- 4 How long will these tests take and what is involved in them?
- 5 Is there anything I should tell my child about these tests which will help prepare him?
- 6 Can he or she eat before coming?
- 7 Are there any precautions I should take either before or after these tests?

Questions about Referrals to Specialists

- 1 Specifically, why is this referral being made?
- 2 Is this a second opinion or are we seeing the specialist for a diagnosis?

- 3 Are there records I should take with me or will they be sent in advance?
- 4 Is this specialist comfortable with children like mine? Has he or she been fully informed about my child's disability or would it be useful for me to give him a call?
- 5 Who will get the reports of this evaluation? Who will be interpreting them? Who will be discussing these reports with me?
- 6 What are this specialist's rates? Can arrangements be made to help cover these expenses?

Questions about Surgery

- 1 What exactly will this surgery do or allow my child to do?
- 2 What are the consequences of not doing it?
- 3 Would there be any advantage in waiting to see if the situation improves?
- 4 How long will my child be in the hospital?
- 5 How long will it take my child to fully recover from this surgery?
- 6 Will we need any special equipment or help at home after release from the hospital?
- 7 What are the possible complications or side effects?
- 8 Should we get a second opinion? Do you think any additional surgery will be necessary?

Questions about Hospitalization

- 1 Can you estimate the length of my child's stay in the hospital?
- 2 Who will be the attending doctors?
- 3 Can I stay with him or her overnight?
- 4 Is there any information I can give him or her now to prepare for this?
- 5 When is check-in time?
- 6 Does the hospital have a program for children explaining about hospitals which would be helpful for my child?
- 7 Will this be covered by my insurance?

Hickson, G.B., Stewart, D.W., Altemeier, W.A., & Perrin, J.M. (1988). "First Step in Obtaining Child Health Care: Selecting a Physician." *Pediatrics*, 81, 333-338. Taken from the National Information Center for Children and Youth with Disabilities (NICHCY). This information is in the public domain.

Appendix Q

Modifying the Environment for Individuals with Physical Disabilities

This list can be used as a starting point to think of numerous accommodations that can be easily arranged to help individuals achieve better in a given situation. Feel free to add your ideas to this list and to share solutions from your own experience about ways to develop accommodations.

- Suggest seating where the individual will be most comfortable and have the greatest access to materials, equipment, lavatory facilities, and emergency exits.
- Inform teacher/supervisor, etc. of any medical considerations for the individual. These include such information as prescribed medication, possible side effects of medication, stamina limitations, physical limitations, and emergency procedures. Then the teacher/supervisor should remember to monitor the effects of medication. Feedback should be provided about classroom and laboratory behavior after medication has been taken by the learner.
- Some individuals may have to be released from class/work periodically to use lavatory facilities, administer insulin injections, take medication, or go to the clinic for a short rest. Be sure the teacher/supervisor knows this.
- It is helpful for teachers/supervisors to release individuals who have wheelchairs, crutches, canes, or braces from class several minutes early so that they may get where they need to go on time. A peer volunteer can help them travel from one place to another. This also fosters positive interpersonal relationships.
- Peer volunteers can be selected to help take notes or review information after direction/instruction has been given.
- If adaptations must be made, ask the individual with the fragile condition or physical disability to help determine exactly what changes must be made. They can often suggest modifications that are inexpensive and easy to create.
- Place materials and supplies to be used by the individual on lower shelves in storage areas.
- Use the demonstration technique whenever possible to provide concrete instructional examples.
- Allow these individuals longer periods of time to complete tasks, if necessary.

- Allow the individuals to tape assignments and tests if they are unable to write.
- Many individuals with physical disabilities have orthopedic appliances such as wheelchairs, canes, crutches, and braces. These appliances should be considered in adapting the program and facilities and/or instruction .
- Overhead projectors produce larger images than writing on a chalkboard.
- Special materials such as large-print books, oversized pencils, pencil grips, clipboards, and easy-to-grasp tools with larger handles should be provided as necessary.
- Adaptive aids such as lapboards for wheelchairs, wrist harnesses to hold pens, and bookholders attached to wheelchairs help individuals adapt to the program.
- Individuals who are in wheelchairs frequently need to redistribute their weight because of poor circulation.
- Provide tutoring by a peer tutor, teacher's aide, parent volunteer, or home-bound instructor if the individual is behind because of frequent absences.
- The other individuals in a given group who do not have a disability should be openly and accurately informed of their disabled peer's particular physical condition and advised how they can assist, if necessary. Honesty is best rather than trying to ignore or hide the condition.
- Many conditions require the use of an orthopedic aid (e.g., wheelchair, brace, cane). Help the teacher/supervisor know how these aids are used and even assist in their maintenance.

Appendix R

Death Education for Teachers: a Refocused Concern Relative to Medically Fragile Children

By Claire Thornton and Junean Krajewski

In today's society, teachers are primary role models for elementary-age students. For these children, most of the day is spent under the care and guidance of an adult whom they regard as a person that they can trust and turn to in time of need. Teachers not only relay a body of academic knowledge to children, but also teach them life skills that will enable them to function as adults in an ever-changing technological society. While academic knowledge is important, it is only one facet of our complex human condition. Children also need to learn healthy emotional responses to life's challenging situations.

One such situation occurs when a terminally ill child becomes a student in a classroom. The issues and challenges surrounding his or her presence and, when applicable, following his or her death, can provide an opportunity for growth on the part of both the teacher and classmates. The term "medically fragile" has been used to refer to children who have life threatening or terminal health-related conditions. Children included in this category may have cancer, cystic fibrosis, muscular dystrophy, or AIDS, as well as other conditions, and frequently may require such specialized care as catheterization, tube feedings, and frequent medication (Kirk & Gallagher, 1989).

The current number of children who could be considered medically fragile is difficult to determine. If the children's needs warrant special services under PL 101-476, those statistics are available. However, many children with terminal illnesses may not opt for or be eligible to receive special services. Others may be included in other categories such as multiple disabilities. Therefore, a brief look at some available statistics on subgroups of this population reveals only a partial accounting of the number of medically fragile children. According to the Centers for Disease Control, the number of children with AIDS in 1988 was 1,065. The projected number for 1991 was 3,000. In addition, The Twelfth Annual Report to Congress on the Implementation of the Education of All Handicapped Act stated that 46,639 children have other health impairments that require special education services (Smith & Luckasson, 1992). With the increased mainstreaming of special

needs youngsters into regular classes and schools, the chances that a teacher will have a terminally ill child in his or her classroom have increased. Such a possibility presents a complex myriad of issues for the field of education in general and for the classroom teacher in particular.

While some literature (e.g., Brennan, 1983; Molnar-Stickels, 1985; Oaks & Bibeau, 1987) maintains that the school is the logical place to educate children about death, there appears to be some debate as to who should be responsible. Numerous articles (e.g., Bascue & Kruger, 1974; Bertoio & Allen, 1988; Getson & Benshoff, 1977; Heath, 1985) discuss the topic as belonging in the counselor's domain while other literature considers the health educator as the focal person for such instruction (Eddy, St. Pierre, Wesley, & Davis, 1985; Molnar-Stickels, 1985). However, it is the teacher who typically has a developed rapport with the children and daily interacts with them throughout the academic school year as a significant adult and role model. It is also the teacher who has expertise in child development and who serves as a vital connecting link between the home, school, and the greater community. Therefore, the teacher, as a trusted and responsible adult, a source of knowledge, and as a person who can network with others in the community, has the resources and the opportunity to comfortably respond to the questions and concerns that children might have on this topic.

Considering the current and increasing focus on the inclusion of medically fragile children in the mainstream, surprisingly little literature addresses the teacher and his or her role as the primary adult encountering the dying child, grieving child, and the parents of both groups. Thus, this article will address the roles and responsibilities of teachers in regard to (a) self-awareness and education, (b) children's understanding and reaction to death, and (c) responding appropriately to parental issues and concerns.

Roles and Responsibilities: An Overview

Whereas many teachers acknowledge that children dealing with a death may need special support, many others may not be aware that such a need exists. Other teachers may question their responsibility or the appropriateness of the subject matter in the school curriculum. Teachers who are unable to help children who are grieving may complicate the process and miss an important opportunity to help children cope with stress (Molnar, 1983; Oaks & Bibeau, 1987). Since teachers maintain constant, almost day-to-day contact with children, they are very significant adults in most children's lives. They can serve as both a support for the children (Oaks & Bibeau, 1987) and an important role model (Cohn, 1987; Cunningham & Hare, 1989).

The importance of helping children perceive and respond to death in a healthy manner is critical to their continuing develop-

ment in emotional, psychological, and intellectual areas (Molnar-Stickels, 1985). While some teachers may choose not to respond (perhaps because they do not know what to say or how to act), such a lack of response may increase children's fears and anxieties (Molnar Stickels, 1985). Obviously the need exists to educate teachers and administrators regarding the roles of the school and school personnel, the importance of the topic in the curriculum, and the resources available. It is important to note that as teachers become more aware of the implications the topic of death may have for them and their classrooms, they may begin to experience some discomfort.

Teachers' Roles and Responsibilities: Self-Awareness

The existence of personal discomfort on the part of a teacher dealing with the topic of death is well substantiated (Cunningham & Hare, 1989; Molnar-Stickels, 1985; Oaks & Bibeau, 1987). Obviously, the teacher's values, feelings, and experiences related to death are potential influences on his or her reaction to children dealing with death. The resolution of these feelings and reactions is important to interacting with a bereaved child. Some experiences that can help a teacher explore his or her own thoughts, feelings, and attitudes may be part of a formal inservice training session that examines death and/or related issues. However, such exploration may be done individually. Suggestions include reading appropriate literature (books or journals), writing a personal obituary, discussing death and dying with other professionals, talking to a mortician, and visiting a nursing home (Bascue & Kruger, 1974; Getson & Benshoff, 1977; Nelson, 1977). As a teacher examines death, religion and its impact on this issue will often become apparent. This may present some concern for the teacher who perceives the connection as breaching the separation between school and religion. To reconcile this concern, the teacher might find it helpful to discuss death with someone of his or her own personal religious background as well as with someone with no religious affiliation or commitment. Such experience might better prepare the teacher to perceive the child's point of view in the religious realm (Getson & Benshoff, 1977).

It seems appropriate to note that with the increase of culturally different children within our schools, some teachers will need to research specific cultural beliefs relative to death. Some research indicates that even a very short teacher in service on death education may result in less fear of death and a more comfortable feeling in discussing death on the part of participants (Molnar Stickels, 1985). As the teacher becomes more comfortable dealing with death, several issues arise. Questions about how to react to children's inquiries and behaviors as well as how to synthesize all the information into meaningful responses to grieving children will arise.

Teachers' Roles and Responsibilities: Education

Many teachers understand the need for their active involvement, have explored their personal feelings, attitudes, and want to respond appropriately with grieving children and parents. The literature suggests that prior to responding, the teacher should have an understanding of the behaviors bereaved children may exhibit, the duration of children's grief, and the stages children may go through in grieving (Eddy, et al., 1985). Additionally, the teacher should be familiar with both the relationship of concepts about death to the developmental stages and the variables that impact the child's progress through the stages. This vital information is summarized below.

Common Student Behavior in Reaction to Death

- Does not complete assignments.
- Frequently asks for the directions to be repeated.
- Complains of headache, stomach aches, loss of appetite.
- Lacks energy.
- May be irritable, nervous, cry, and have mood swings.
- May exhibit inattention, daydreaming.

Children: Understanding and Reacting to Death

When children experience the death of a classmate, they struggle intellectually with understanding what has transpired and emotionally with accepting the loss. First of all, it is important to realize that children's understanding of death is directly related to their cognitive development. Children between the ages of three and six are in Piaget's Preoperational Stage of development. At this stage, the child is egocentric and may believe that he or she is personally responsible for an individual's death by having thought, "I wish she'd go away" or "I wish he'd drop dead." The children may struggle with guilt if the thoughts and feelings become a reality. At this level, the child does not understand that death is forever because the child does not have a developed sense of time. Children think that the dead person is still living in the coffin and becomes active at night. To summarize, children at this level of cognitive development do not perceive death as a natural, irreversible, and universal part of life.

In comparison, children who are between the ages of seven and ten are in Piaget's Concrete Operational Stage. Children at this level are concrete in their thinking and personify death as a shadowy, sneaky figure – a skeleton or a ghost who appears late at night. Because they personify death, they believe that they can run away from "it", outsmart "it", or hide from "it." They are also inquisitive as to what death means and are open to receiving honest and direct answers. They may ask questions that seem gruesome

such as, "Do worms eat through the coffin?" (Garanzini, 1987). The following example illustrates why teachers should respond to children's questions without using any figurative language.

One teacher told her primary grade class that a student had died "because God picks the most beautiful flowers in the garden and takes them to heaven." One child, at the concrete level of cognitive development, became a behavior problem in order to guarantee he wouldn't be picked (Breig, 1987). At this age, however, children perceive death as final and around the latter ages of this level, inevitable.

Around the age of twelve, children enter Piaget's stage of Formal Operations and have the cognitive ability to think abstractly about the concept of afterlife and fully comprehend what death means (Garanzini, 1987; Molnar, 1983). It is important for the teacher to consider the children's cognitive development prior to responding to their questions and concerns. While literature examines a child's reaction to death, classmates will also have concerns and problems dealing with the possible and impending death of a medically fragile peer. In this instance, the level of cognitive development should also be considered. One fifth-grade teacher reported a range of emotions among his students when a peer was diagnosed with leukemia. Reasoning at the concrete operational level, many students believed that death could be avoided, and therefore the illness and subsequent death were the result of irresponsible and negligent care. These students expressed concern that leukemia could be contagious and were fearful of attending school or interacting with their classmate. A visit to the classroom by one of the attending physicians who explained leukemia and the child's treatment helped answer these students' questions and allay their fears.

Children at either the preoperational or formal operations stages of development would express other concerns that would necessitate different responses. Also, depending on the developmental stage of the children, the topic of death could be discussed in the classroom through the use of literature. Ordal (1984) presents a comprehensive list of appropriate books or stories that deal with death in a positive way. Other interventions, as well as a list of agencies and organizations and films/videos, are included in Heath (1985). See the section below for various ways to help children.

Guidelines for Helping a Child

- Encourage children to express their feelings but don't push for too much or require that they do so.
- Be honest. Answer questions truthfully and express your own emotions honestly.
- Keep it simple. Discuss death in terms children can understand. Don't give them more information than they can handle at their developmental level.

- Relate to children at their developmental level. If you're unsure of their level, ask them for their interpretation of what happened.
- Be patient. Be aware that children may repeat the same questions as they seek reassurance and deal with confusion and fear. Also remember that the length of grieving differs from child to child and may last for some time.
- Don't pre-establish expectations. Each child deals with death differently.
- Do suggest some ways a child can memorialize the person such as planting in that person's honor, drawing a special picture, or writing something about the person.
- Accept the child's feelings, perceptions, and reactions. Allow for differences of opinion, doubt, and questions.
- Refer the child, and perhaps the parents to other support people or services if necessary.
- Prepare children for the continuation of their life. Reassure them that they will feel better after a time and that the time differs from person to person. Children should be assured that, in time, they will be able to play and have fun and that doesn't mean they love the person any less (Breig, 1987; Cohn, 1987; Cunningham & Hare, 1989; Eddy et al., 1985; Faivre, 1981; Garanzini, 1987; Heath, 1985).

Providing Parental Assistance

Teachers should also be prepared to respond to parent concerns. Teachers may be asked to respond to the parents of the dying child or the deceased child as well as to the parents of grieving classmates. Each situation will require a slightly different perspective. Open communication will enable the teacher to share supportive materials and information with concerned classmates that is in keeping with the dying or deceased child's family's request for privacy. The topic of death has long been regarded as "taboo" in our society. Certainly its inclusion within the school curriculum might generate some controversy and discussion. However, it is apparent that death is a reality that both children and adults must perceive in the most accurate way possible. While the topic can be addressed before or after a death, the literature overwhelmingly addresses the need for well-prepared teachers who can assist and support children as they encounter this stressful occurrence. Teachers need self-awareness regarding their own attitudes and concerns regarding this topic. They need an understanding of children's perception of death and how to respond appropriately. Finally, they need to be able to address parental issues and concerns. Classroom teachers are the connecting link between the school, home, and the greater community. Because of this, they

fill multifaceted roles. They are interactive facilitators, informal classroom counselors, child development specialists, and resourceful networkers. They are significant adults to the children they serve. With appropriate preparation, teachers can have a positive impact in teaching children healthy emotional responses to one of life's most challenging situations. With the inclusion of an increased number of medically fragile children in the mainstream of our schools, the time for an active response is now.

Ways to Assist Parents

- Contact the parent by phone and/or by note to express concern or sympathy and to open channels of communication.
- Schedule a parent conference if desired by the parent.
- Distribute helpful articles focusing on parent concerns.
- Recommend children's books (to be shared at home) that deal with the topic in a sensible manner.
- Distribute written guidelines and/or suggestions especially if an individual situation requires more specific attention.
- Make available a list of mental health clinics and/or professionals available for assistance.

Reprinted with permission. C. Thornton & J. Krajewski. "Death Education for Teachers: a Refocused Concern Relative to Medically Fragile Children", *Intervention in School and Clinic*, 29, 1, 31-35, 1993, PRO-ED, Inc.

Appendix S

Estimated Prevalence of the Major Uncommon Diseases & Conditions in Children

The conditions listed below are considered "uncommon" because they each have a frequency of less than one percent in the child population. This information was adapted from Gortmaker, S.L., & Sappenfield, W. Chronic Childhood Disorders: Prevalence and Impact. *Pediatric Clinics of North America* (1984) 31: 3-18.

<i>Disease/Condition</i>	<i>Prevalence per 1,000 Children</i>
Congenital heart disease	7.0
Seizure disorders	3.5
Cerebral palsy	2.5
Arthritis	2.2
Paralysis from injury	2.1
Diabetes mellitus	1.8
Cleft lip/palate	1.5
Down syndroms	1.1
Blindness	0.6
Mental retardation due to fragile x chromosome	0.5
Sickle cell disease	0.5
Neural tube defect	0.5
Autism	0.4
Cystic fibrosis	0.3
Neurofibromatosis	0.3
Hemophilia	0.2
Duchenne muscular dystrophy	0.1
Acute leukemia	0.1
Deafness	0.1
Other hereditary metabolic disorders	0.1

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American Diabetes Association, Diabetes Information Service Center, 1660 Duke Street, Alexandria, VA 22314. Telephone 800/232-3472.

American Lung Association, 490 Concordia Avenue, St. Paul, MN 55103. Telephone 800/642-LUNG, 612/227-8014.

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Cunningham, B. & Hare, J. (1989). Essential elements of a teacher inservice program on child bereavement. *Elementary School Guidance and Counseling*, 23, 175-182.

Cystic Fibrosis Foundation, Foundation Office, 6931 Arlington Road, Bethesda, MD 20814. Telephone 301/951-4422.

Eating Disorders Institute, Methodist Hospital, 6500 Excelsior Boulevard, St. Louis Park, MN 55426. Telephone 612/932-6000

Eating Disorders Program, Riverside Medical Center, Riverside & 25th Avenue S, Minneapolis, MN 55454. Telephone 612/371-6600.

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